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ABSTRACT

The first section of this volume, designated "the state of the art 1987," contains four papers addressing issues of continuing importance to those who work with developmentally handicapped children: (1) "Passive Exposure to Cigarette Smoke Adversely Affects the Health of Fetuses and Infants" (James E. Haddow and Paula K. Haddow); (2) "The Social Security Supplemental Security Income (SSI) Program for Disabled Children" (Judson F. Force and Holly Allen Grason); (3) "Health-Education Collaboration for Children 0-5" (Pascal Trohanis and Phyllis Magrab); and (4) "Child Abuse and Developmental Disabilities" (Bruce Cushna). The second section features linkages between State Title V Programs and University Affiliated Facilities through descriptions of five selected Special Projects of Regional and National Significance (SPRANS) funded by the federal Division of Maternal and Child Health: (1) "A Community Collaboration Approach for Developing Early Intervention Services in Oklahoma" (Ronald K. James); (2) "Toward Strengthening Nutrition Services in Region X (Arizona, California, Hawaii, Nevada) for Children with Chronic Illness and Handicapping Conditions" (Marion Taylor Baer); (3) "Youth in Transition Project" (Peggy West); (4) "Continuing Education for Occupational Therapists Working with Children and Their Families" (Shirley Vulpe); and (5) "New Directions: Serving Children with Special Health Care Needs in Massachusetts" (Allen C. Crocker). (VW)

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DEVELOPMENTAL HANDICAPS: PREVENTION AND TREATMENT IV

A Cooperative Project Between University Affiliated Facilities and State MCH/CC Programs

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The UAF Network

University Affiliated Facilities (UAFs) are programs established to train personnel in the interdisciplinary approach to the delivery of services, to conduct research and to provide exemplary services related to persons with developmental disabilities and other multiply handicapping conditions. There are 55 programs in 38 states and the District of Columbia and many of the UAFs relate to programs in other states.

The American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP) is the national association of UAFs.

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Introduction

In selecting just four topics from the multiple issues that relate to developmental handicaps, the decisions made sometimes result in papers which are superseded, by publication time, by more critical isues or new information that comes available during the writing and publishing process. This fourth edition of Developmental Handicaps: Prevention and Treatment, however, contains four articles which are of truly continuing importance. For example, the selection of the paper, "Health-Education Collaboration for Children 0-5," was made well before the passage of P.L. 99-457 and its Part H program for handicapped infants and toddlers. If anything, the existence of that law and the currency of efforts to plan and implement for the coming fiscal year provide greater urgency for providing this information now than at the time the topic was selected.

On a daily basis, those who work with children with disabling conditions are faced with the certain knowledge that some children will "fall between the cracks." The authors of "The Social Security Supplemental Security Income (SSI) Program for Children" have, for perhaps the first time, described the benefits and eligibility provisions of the SSI Childhood Disability Program in clear and understandable language. We believe this paper will become a reliable reference companion for those who deal with this program.

Two papers, "Passive Exposure to Cigarette Smoke Adversely Affects the Health of Fetuses and Infants" and "Child Abuse and Developmental Disabilities" more directly focus on prevention. Causality in the first instance is clear and well documented. In the second, causality remains at the center of continuing debates. In both instances it is essential to adopt and implement responses that will effect changes in behavior to prevent disability.

Following the state-of-the-art papers, is a section in which we feature the linkages between State Title V Programs and University Affiliated Facilities,

this year through the description of selected Special Projects of Regional and National Significance (SPRANS) funded by the Division of Maternal and Child Health. The topical areas of these projects range from community networking for early intervention services (in Oklahoma) to strengthening nutrition services (in Region IX). Continuing education for occupational therapists and youth in transition projects are also presented.

Last, but not least, is an article, "New Directions: Serving Children with Special Health Care Needs in Massachusetts," describing a platform for serving children with chronic illness and disabilities which was presented in a public hearing at the Massachusetts State House. This platform, which is anticipated to result in the State taking a leadership role in more effective family support and fiscal advocacy for children and families with these needs, is the final step in a multi-year SPRANS project to review the public mandate for services to children with special health care needs in Massachusetts. Many projects result in superb reports which are seldom known outside the service community; Project SERVE has broken through that barrier to bring the needs to the attention of the decision-makers on their own turf.

Finally, appreciation is expressed to the authors of the papers printed herein and to members of the MCH Consortium Project Steering Group for their support and assistance in the writing and review of this publication.

Silver Spring, Maryland — Elaine M. Eklund

Boston, Massachusetts — Allen C. Crocker

I.
DEVELOPMENTAL ISSUES:
THE STATE OF THE ART 1987

PASSIVE EXPOSURE TO CIGARETTE SMOKE ADVERSELY AFFECTS THE HEALTH OF FETUSES AND INFANTS

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Introduction

In the United States, cigarette smoking is the single most important environmental agent that causes human disease. Its effects are far-reaching and include an increased risk of lung cancer, heart disease, chronic lung disease, stroke, and other cancers. Recently, evidence has accumulated that documents adverse health consequences related simply to breathing another person's smoke. In this article attention is focused on two population groups whose health has been documented to be adversely affected by exposure to other people's smoke: fetuses and infants. In both of these instances, the mother's smoking is the most significant contributor, and in both instances the mother is the individual who needs to take responsibility for removing that exposure. Given the amount of evidence that has accumulated on biological and pathophysiological consequences to fetuses and infants as a result of environmental cigarette smoke, it is now time for the health community to take concerted action to minimize such exposure.

Fetal Morbidity and Mortality

Since the first report of an association between maternal smoking and decreased birthweight (Simpson, 1957), considerable evidence has accumulated that supports the adverse influence from maternal cigarette smoking on offspring in terms of both morbidity and mortality. By 1980 the evidence was convincing

enough that the Surgeon General unequivocally stated that a causal, dose-response relationship exists between maternal smoking and infant injury and death (Tye, 1986; United States Department of Health and Human Services, 1980).

However, despite the fact that cigarette smoking is the most common known harmful exposure during pregnancy, an estimated 25.5 percent of pregnant women continue to smoke (Werler, Pober & Holmes, 1985; Prager, Malin, Speigler, Van Natta & Placek, 1984). For this reason, it is worthwhile to obtain as much insight as possible into the adverse effects of maternal smoking as a step toward helping women of childbearing age to understand why it is important to stop smoking or not to start.

Decreased Birthweight

It has been well established that maternal smoking has an adverse effect on fetal growth and development. Low and depressed Apgar scores at one and five minutes after birth are found almost four times as often in infants of women who smoke 41-60 cigarettes per day during pregnancy as in infants of non-smokers (NICHD, 1983). Furthermore, women who smoke cigarettes during pregnancy deliver infants whose birthweight is, on average, 150-200 grams lower than that of infants born to non-smoking women (Stein & Kline, 1983). This appears to be a dose-response effect, with 10-20 cigarettes per day throughout pregnancy producing a birthweight reduction of approximately 200 gm (Meyer, Jones & Tonascia, 1976). The relationship between decreased birthweight and smoking remains after correcting for such confounding factors as maternal age, parity, weight gain, weight and/or height, socioeconomic status, race, and sex of offspring (Meyer et al., 1976; Lowe, 1959; Frazier, Davis, Goldstein & Goldberg, 1961; Underwood, Kesler, O'Lane & Callagan, 1967; DHEW, 1973; Cardozo, Gibb, Studd & Cooper, 1982). Women who stop smoking during the first half of their

pregnancy deliver infants whose birthweights average close to those of non-smokers (Sexton & Hebel, 1984).

The Pathophysiology of Smoking in Pregnancy as It Relates to Decreased Birthweight

Placental blood flow, fetal activity, and fetal breathing movements all decrease when a pregnant woman smokes cigarettes, and fetal adrenergic activity increases (Hill & Kleinberg, 1984). Placental vascular histologic changes have also been documented. Prostacyclin synthesis is severely depressed in the neonate's umbilical artery when the mother smokes, and it has been suggested that this may be responsible for decreased placental perfusion and umbilical artery flow (Dadak, Kefalides, Sinzinger & Weber, 1982). SP-1, a pregnancy protein produced by the placenta, has been found to be significantly reduced in smokers in both the second and the third trimesters (Lee, Grudzinskas & Chard, 1981).

Mortality

Perinatal mortality is usually defined as a reproductive loss after the twentieth week of gestation and before the seventh day of life. Although studies on the relationship between smoking and perinatal mortality have shown conflicting results, some associations have emerged (Meyer & Tonascia, 1977; Rantakallio, 1978). For example, smoking seems to affect the fetus of a mother in a low socioeconomic status group more than the fetus of a mother in a high socieconomic status group; and women who are at increased risk for perinatal mortality because of low social class, advanced maternal age, and history of a previous loss are at an even greater risk if they smoke (Comstock, Shah, Meyer &

Abby, 1971). In a large sample of women from all social classes, those women who decreased or stopped smoking during pregnancy had infants with lower rates of perinatal mortality than women who did not reduce their cigarette consumption (Butler, Goldstein & Ross, 1972).

Vaginal bleeding during pregnancy, abruptio placentae, placenta praevia, prematurity alone, pneumonia, and premature or prolonged rupture of membranes have been found to be the cause of perinatal mortality in a greater proportion of the offspring of smokers than non-smokers (Meyer & Tonascio, 1977; Naeye, 1980; Andrews & McGarry, 1972). Cessation of smoking during pregnancy was found to result in a decreased risk for abruptio placentae and placenta praevia (Naeye, Harkness & Utts, 1979).

The spontaneous abortion rate is higher in women who smoke during pregnancy than in non-smokers (Butler et al., 1972; Rantakallio, 1969; Yerushalmy, 1972; Comstock et al., 1971). Data from the Ontario Perinatal Mortality Study, taking into account a number of possible confounding variables such as maternal age, parity, history of previous abortions, alcohol use, and exposure to waste anesthetic gases, show an overall 27 percent higher spontaneous abortion rate among women who smoke during pregnancy. Again, a dose-reponse relationship has been reported, with a 20 percent higher risk associated with fewer than 20 cigarettes per day and a 35 percent higher risk with more than 30 cigarettes per day throughout pregnancy (Himmelberger, Brown & Cohen, 1978; Harlap & Shiono, 1980).

By and large, abortuses of women who smoke during pregnancy are chromosomally normal, indicating an increased rate of abortions among otherwise viable products of conception, due to smoking (Werler et al., 1985). Kline, Levin, Shrout, Stein, Susser & Warburton (1983) found that women smokers under the age of 30 are less likely to have a chromosomally abnormal abortus than non-

smokers, while, conversely, those women over 30 who smoke are more likely to have a chromosomally abnormal abortus than non-smokers. Whether this indicates that smoking affects meiosis or that it affects the survivability of an embryo/fetus in utero or whether it affects both is unclear (Werler et al., 1985).

Malformations

Studies attempting to examine the relationship between maternal smoking and the occurrence of congenital malformations have produced conflicting results. The three studies that have reported a positive association between maternal smoking and the occurrence of all major malformations analyzed only live births (Himmelberger et al., 1978; Christensen, 1980; Kelsey, Dayer, Holford & Bracken, 1978); the studies that accounted for both live births and stillbirths found no such association (Andrews et al., 1972; Mulcahy, 1968; Evans et al., 1979; Chung & Myrianthopoulos, 1975).

A possible association between neural tube defects and smoking during pregnancy has been looked at, as have "central nervous system defects," orofacial clefts, congenital heart disease, and limb reduction defects. The studies have produced contradictory results, thereby making it difficult to conclude either that smoking is important as a teratogen or that it is not associated with teratogenic effects (Werler et al., 1985).

Early Childhood Morbidity and Mortality

Studies over the past decade have reported an increased frequency of physical problems, intellectual impairment, and behavioral abnormalities in children whose mothers smoked during pregnancy.

Physician and Hospital Visits

Children of mothers who smoke during pregnancy visit the doctor more often and have more hospital admissions during the first year of life than children of non-smokers. As in other instances, a dose-response effect is apparent. Children of women who smoked 10 or more cigarettes per day through at least the end of the second month of pregnancy were found to have, on average, 0.83 visits to doctors and 0.39 hospitalizations during the first year of life, compared to 0.61 visits to doctors and 0.15 hospitalizations for children of non-smokers (Rantakallio, 1978). Furthermore, the study found that within each social group, children were more often hospitalized, and the hospital stays were longer, if the mother smoked during pregnancy than if she did not. The most common diagnoses for hospitalization in children whose mothers had smoked during pregnancy were pneumonia, bronchitis, pharyngitis, sinusitis, eczema, urticaria, and infectious diseases of the skin and subcutaneous tissue. The more frequent hospitalization of children of smokers because of respiratory diseases was most obvious below the age of one year.

It has not yet been possible to determine whether the childhood morbidity associated with mothers' cigarette smoking is due solely to environmental exposure following birth or whether maternal smoking during pregnancy is also a contributing factor.

Effect of Passive Smoking on Childhood Morbidity

Both controlled and uncontrolled studies have consistently found a direct relationship between passively inhaled smoke and childhood asthma, persistent wheezing, and respiratory illness in the first and second years of life (Cole, 1986; Gortmaker, Klein-Walker, Jacobs & Ruch-Ross, 1982; Horwood, Fergusson &

Shannon, 1985; Weiss, Tager, Speizer & Rosner, 1980; Pedreira, Guandolo, Feroli, Mella & Weiss, 1985; Fergusson, Horwood, Shannon, Taylor, 1981; Tager, Weiss, Munoz, Rosner & Speizer, 1983). This evidence can be considered conclusive and forces the conclusion that everything possible be done to keep infants away from environmental cigarette smoke.

Tager et al., in a longitudinal study of 1100 children, found a significant effect of maternal smoking on the change in a child's forced expiratory volume in one second (FEV)1 after controlling for the previous level of FEV1, age, sex, height, change in height, and the child's personal cigarette smoking habit. His data suggest that after five years of age, the lungs of non-smoking children whose mothers smoke grow at only 93 percent of the rate in non-smoking children whose mothers do not smoke. These findings strengthen the possibility that the effect of maternal smoking in the first two years of the child's life may be indirect. Most of the increased occurrence of respiratory illness in the children of mothers who smoke, as compared with the children of mothers who do not smoke, is in the first two years of the child's life, a time when the lung may be particularly vulnerable to the long term adverse consequences of such illnesses. "Thus, the observed effects of maternal smoking may be the consequence of structural changes that result directly from acute lower-respiratory illness early in childhood or indirectly from the long-term consequences of alterations in airway reactivity that may result from such illnesses" (Tager et al., 1983).

Childhood Cancer

A dose-response relationship has been found between the number of cigarettes smoked per day by the mother during pregnancy and cancer risk in the

offspring (Stjernfeldt, Berglund, Lidsten & Ludvigsson, 1986; Stewart, Webb & Hewitt, 1958; Neutel & Buck, 1971). When all tumor sites were considered, the overall risk for cancer in children exposed to 10 or more cigarettes per day during pregnancy increased by 50 percent. For Wilms' tumor, non-Hodgkin lymphoma, and acute lymphoblastic leukemia, the risk was doubled.

"Wilms' type tumors have been induced in rodents by transplacental N-ethylnitrosourea. This is of special interest since nitrosamines were the first tobacco-specific carcinogens to be identified. Other possible and very potent carcinogenic effects may be obtained by alpha radiation from 210Po and 210Pb, which are highly concentrated in cigarette smoke. From laboratory animal data it can be concluded that: a variety of tumors, including leukemia, can be induced by transplacentally acting carcinogens; many of these carcinogens are known components of tobacco smoke: the transplacental carcinogenic effect may be exerted at lower doses than those required in adult animals; and prenatal exposure tends to enhance the effect of subsequent exposures to the same or other carcinogens during postnatal life" (Stjernfeldt et al., 1986).

As in the case of increased occurrence of respiratory disease in children of smoking mothers, the influence of passive childhood exposure to cigarette smoke cannot be ruled out as a contributing factor to increased risk for childhood cancer. However, available data strongly suggest that maternal smoking during pregnancy may increase the risk for childhood cancer in their exposed offspring.

Effects on Behavior and Intellectual Development

Many parental factors contribute to a child's behavioral and mental development, and these should be taken into account in any attempt to evaluate the effect of maternal smoking during pregnancy on subsequent childhood behavior

and intellectual development. Several studies have reported small intellectual differences between the children of smokers and non-smokers, but these studies have not taken into account such factors as genetic influences and differences in child-raising practices between smokers and non-smokers. For instance, women who smoke reportedly drink more alcohol, have higher anxiety scores, divorce more often, and change jobs more frequently than non-smokers (Yerushalmy, 1971). Naeye and Peters (1984) analyzed data from a large prospective collaborative perinatal study that took these factors into account and that looked also at several biological markers that are known consequences of smoking and that correlate with children's behavioral and cognitive abnormalities. The markers they chose were fetal growth retardation, a long recognized consequence of maternal smoking during pregnancy, and hemoglobin levels in neonates that progessively increase with the number of cigarettes mothers smoke during pregnancy.

The study results showed that children of mothers who smoked during pregnancy had slightly lower scores on spelling and reading tests, more often had short attention spans, and were more often hyperactive than children of non-smokers. Furthermore, among children of smokers, a correlation was found between the two biochemical markers and children's subsequent behavior. Children of smokers who were born at full term and who subsequently developed behavioral abnormalities had significantly higher neonatal hemoglobin levels and lower birth weights than smokers' children whose behavior was normal. These correlations were not present in the offspring of non-smokers. These findings strengthen the possibility that the cognitive and behavioral abnormalities found in children of women who smoke during pregnancy are caused by maternal smoking.

"Possibly fetal hypoxia contributes to the genesis of smoking-related behavioral abnormalities because increased hemoglobin levels are a likely

consequence of fetal hypoxemia. There are several mechanisms by which maternal smoking can make the fetus hypoxic. Both the nicotine and carbon monoxide that women absorb from cigarettes reduce the delivery of oxygen to fetal tissues. Nicotine reduces uteroplacental blood flow and carbon monoxide produces substantial levels of carboxyhemoglobin in the fetal blood" (Naeye and Peters, 1984).

Biochemical Markers of Cigarette Smoking Exposure

In recent years, considerable effort has been directed at developing biochemical tests that can reliably measure cigarette smoke exposure, both in cigarette smokers themselves and in non-smokers exposed to other people's smoke. Markers such as carboxyhemoglobin and thiocyanate have provided some useful information about smoking, but both these markers are influenced not only by cigarette smoke but by other environmental agents as well. This shortcoming interferes with both the sensitivity and the specificity of these two tests, especially in relation to passive smoking exposure. Nicotine is specific to tobacco smoke and has also been measured with some success, but it has two major shortcomings: it has a short circulating life in the body (about 30 minutes), and it is so ubiquitous on fingers and clothing of smokers that it can contaminate a laboratory and render the test system useless. One laboratory in London was actually closed down for over a year, after a maintenance person smoked a cigarette in the room while performing a minor repair. The most promising marker to date is cotinine, a metabolic product of nicotine produced in the liver. Cotinine has a circulating half-life of about a day, making it very reliable to measure average exposure to smoke, and it can be measured accurately in passively exposed as well as actively exposed individuals. Preliminary studies have demonstrated cotinine measurements to be more reliable

than smoking history when assessing both exposure and health consequences. Biochemical markers are likely to be applied more and more frequently both to study smoking and to help people modify smoking behavior, and this type of testing will be very helpful in assisting the community both to explain environmental cigarette exposure to young families and to monitor progress in reducing exposure.

Public Health Implications

Given the weight of evidence concerning adverse consequences during early life from environmental cigarette smoke, it is important that the health community redesign its patient management protocols to include assessment and information about this public health issue. There is a need for caution, however, in that there can be a temptation to take the discussion beyond health to morality, thereby unnecessarily imposing guilt upon individuals struggling to reduce their dependence on a deeply ingrained habit. Cigarette smoking is a pervasive societal health problem that will not disappear overnight, and the most reasonable approach will be to balance persistence with helpfulness and common sense.

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THE SOCIAL SECURITY SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM FOR DISABLED CHILDREN

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Introduction

In order that children with disabling conditions can receive mandated public services, it is important that professionals working in Title V supported programs, as well as those serving disabled children in the health care community at large, are familiar with programs such as Supplemental Security Income (SSI) under Title XVI of the Social Security Act. Both the pediatric and specialty medical care communities are gatekeepers to appropriate and adequate service systems. Without careful attention on the part of the providers of specialty health care, the danger exists that some children will "fall between the cracks." This article, hopefully, will help to create a new awareness as to the current status and future potential of the SSI program for disabled children.

Social Purpose of the SSI Childhood Disability Program

Children, by virtue of their age, are dependent on adults or on existing social institutions to meet their basic living and developmental needs. This problem of dependence is compounded for children with disabilities and their families. If they are to escape permanent dependency, such children must receive early health care, basic skill training, and social experiences which promote self-reliance.

Over the past 50 years various federal programs have been established to serve disabled children and their families. Major Social Security health programs under the Act include the Crippled Children's Services program provision mandated under Title V and Medicaid under Title XIX. Education and related services were provided for under P.L. 94-142, the Education for Handicapped Children Act of 1975 and the reauthorization of this Act, P.L. 99-457, which authorizes early intervention services for handicapped infants or those at high risk for developmental delay. Habilitative services were also made available under P.L. 95-602, the 1978 extension of the Developmental Disabilities Act. In addition, states, individually and in conjunction with the Federal government, provide an array of programs providing assistance to children with chronic handicapping conditions and their families.

These programs are of substantial assistance to low income families with disabled children through increased access to, and provision of, quality health, habilitation, educational, and social services. However, limitations imposed by federal and state appropriation levels for these programs leave many gaps in coverage of the full range of services needed to care for these children. The 1972 enactment of the Title XVI SSI Amendments to the Social Security Act, P.L. 92-603, addressed a major gap at the Federal level. Up until that time a missing public policy initiative was that of cash assistance to low income disabled children to ensure that their families or guardians could provide a more healthy and supportive environment for their children with special health related needs.

The Title XVI amendments, which provided supplemental income for children under age 18, came late in the evolution of Social Security disability programs. The 1950 Amendments to the Social Security Act had initially set the stage for such programs by providing for grants-in-aid to the states for public assistance to permanently and totally disabled, and needy, adult individuals. In 1956, the

Title II Social Security disability insurance program was added to the original retirement and survivors insurance program and provided for income for persons age 50 - 64 who had become disabled. In 1958, cash benefits for the dependents of disabled workers were added; the age 50 requirement for the disabled was dropped in 1960. This Title II program, however, provided cash benefits only for those disabled workers (and their dependents) who paid into the Social Security trust fund through FICA contributions on their earnings. Thus, the Social Security program for the disabled was aimed originally only at those who had an "earned right" to disability insurance benefits.

The SSI program under Title XVI for the Aged, Blind and Disabled became effective January 1, 1974, and replaced the state programs of public assistance to this population. Under the SSI program an individual was not required to have prior or recent employment experience in Social Security covered employment. Funded from general revenues, the program was intended to supplement the income of needy individuals who were blind or disabled or over age 65 and received no benefits or only minimal benefits under Social Security insurance programs. The program thus was fundamentally structured as a public assistance program, basing eligibility on financial need as opposed to the "benefits due" aspects of an insurance program.

Under SSI, for the first time in the nation's history, a federal program of cash assistance was provided to low income medically disabled children from infancy through age 17 in recognition of their special needs. The House Ways and Means Committee Report on the SSI legislation stated that "disabled children who live in low income households are certainly among the most disadvantaged of all Americans and that they are deserving of special assistance in order to help them become self-supporting members of our society. Making it possible for disabled children to get cash benefits under this program would be appropriate

because their needs are often greater than those of nondisabled children; the Senate Finance Committee emphasized this need only in the health care area. By placing the program of cash benefits for disabled children under the mandate of SSI, the program was established specifically for children with medical disabilities living in low income families rather than low income children at large served under state welfare programs. SSI eligibility also was designed to lighten the burden of specialized and expensive health care costs by establishing provisions for automatic Medicaid eligibility.

The specific intent of Congress, then, in regard to the inclusion of the disabled child population in the SSI program is reasonably clear. Although this age group was included in the final approved legislative package "late in the game," and much of the congressional history remains less than completely documented, the goals of the SSI program for disabled children are considered to be essentially consistent with those of the disability program as a whole; that is:

1. to compensate persons with medical impairments that significantly interfere with age appropriate basic work capacity (i.e., to pay benefits for medically related limitations in ability and aptitude necessary to do expected jobs)
2. to promote the rehabilitation or restoration of disabled persons to appropriate productive basic work status (i.e., to help individuals to become self-sufficient and productive).

For children, a further goal and basic purpose of the Act is understood to be a reduction of the additional deleterious environmental effects of low family income on growth and development of the disabled child by guaranteeing them direct cash assistance. Equity was to be established and assured by setting forth and monitoring compliance with federal standards and guidelines for uniform eligibility determination by the states.

Medical Impairment Program Eligibility

Disability under Social Security is defined as "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of not less than 12 months." While there are 3 components to this definition, 1) absence of substantial gainful activity, 2) the presence of a medically determinable impairment, and 3) expectation of death or duration of 12 or more months, the central requirement is that the individual have a medically determinable condition and related functional impairment that meets established severity criteria. The SSI statutory definition of a disabled child is "a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity to the disabled adult who is unable to participate in SGA and who meets the duration requirement."

SGA in an adult is defined as work that 1) involves doing significant and productive physical or mental duties, and 2) is done (or intended) for pay or profit. Since children are not expected to be doing gainful or remunerative work, the concept of evaluating childhood claims on the basis of comparable or equivalent remunerative work-limiting disorders of adulthood would have been inappropriate to consider. Therefore, another and more basic meaning of SGA for an adult was used in considering the application of the law for disabled children. The meaning that was derived for this purpose was the ability to function in the primary work activity appropriate for age. Primary work activity in childhood was, thereafter, defined as the ability to develop and mature within accepted age appropriate norms.

In childhood, the function of development and maturation is described in

terms of expected biological and behavioral norms. These norms reflect several processes that can be observed and measured. Processes include 1) growth -- increases in size and maturation of physical and physiological characteristics, 2) cognitive, motor, and emotional development, 3) mastering basic learning and communicative skills, and 4) socialization. Any medical condition that results in a departure from these norms can be evaluated according to established impairment criteria which have been published in The Childhood Listings, Part B, Medical criteria. The Part B Childhood Listing is the medical reference base for evaluating physical or mental impairments that are known to interfere with age appropriate development or maturation, and is based on pathological findings or limitations of function.

On the one hand, while espousing developmental progress as a primary basis for disability determination, the Listings reflect in many instances quite specific laboratory and other pathological evidence of severe impairment (e.g., listing 104.04 C, cyanotic congenital heart disease with a chronic hematocrit of at least 55 percent or arterial oxygen saturation of less than 90 percent at rest; or listing 106.02 A, chronic renal disease with persistent elevation of serum creatinine to 3 mgm. per deciliter; or listing 101.05 B, scoliosis with a major spinal curve measuring 60 degrees or greater). Such criteria were established, to a large extent, as a means to simplify the adjudication process by not otherwise requiring more detailed and explicit evidence of developmental dysfunction. The assumption is made that medical impairment, as measured by a severe level of organicity, almost surely is associated with a developmental burden imposing significant restriction on development and maturation.

When regulations were first promulgated, the preamble of Section 416 of Title XVI expressed recognition of the fact that the manifestations of certain disease processes in children may be different than in adults even where the diagnosed

condition is the same. Therefore, although criteria for determination of eligibility as developed for adults in Part A of the listing can be utilized in childhood cases, where additional or other criteria are necessary to give appropriate consideration to the particular effect of disase processes in childhood, Part B of the listing was created to provide criteria for evaluating such cases. The listing describes not only the medical conditions but also includes the signs, symptoms, and test findings that establish the requisite level of severity for eligibility. In brief, the listing is an adjudicative tool that defines the medical evidence required to establish the existence, severity, and duration of impairments for purposes of a disability decision.

Medical evidence which substantiates that an impairment meets or equals the intent of a disability listing is the most critical determinant in the adjudication process. For example, although children with Down syndrome (DS) are known to manifest features of mental retardation beginning in infancy, complete documentation of other biological and behavioral dysfunction should also be provided at the time of filing. This has proven to be an issue of concern to families and advocates particularly in cases of very young infants where deviations from normal mental development are more subtle and variable than in later infancy. A child with DS may be denied benefits based on the Mental listing criteria (112.05) at five to six months of age. It is possible, however, that at this same age significant impairment might be manifested based upon adequate documentation of interference of linear growth (100.02), severe neuromuscular abnormalities such as hypotonia or postural reaction deficit affecting development (111.06), or associated conditions involving the cardiac, endocrine, gastrointestinal, or other body systems. Therefore, while virtually all children with DS will eventually be found disabled, a finding of disability for the very young infant rests largely upon having complete evidence with which to evaluate all affected body systems. In general, a major problem in properly

adjudicating claims of children with conditions likely to produce multiple impairments is the great potential for overlooking the need to consider more than a single system in the evidentiary documentation process.

Application, Adjudication and Appeal Processes

The process for determining eligibility for SSI childhood benefits is a multi-tiered, or sequential, process. The inital step takes place at the local Social Security office where the applicant states the general nature of the impairment and provides the names and addresses of the physicians and medical centers where treatment has been received. The local Social Security office reviews the applicant's non-medical eligibility factors, including assessment of income and resources as part of the means test for SSI eligibility. The claim may be denied at this stage if the applicant is found to be ineligible based on these non-medical considerations. Claims from financially eligible applicants are then forwarded to the Disability Determination Services (DDS) of the State agency designated to perform the disability evaluations.

A disability examiner and physician team, both trained in the disability process, make the initial determination of disability by deciding whether a disabling impairment is present. This decision is made based upon a review of the medical evidence gathered from the physicians and other providers listed by the applicant. If the evaluators believe that there is insufficient evidence to make a determination, the applicant may be asked to have a consultative examination (CE) performed by a provider selected by the DDS agency. CEs are generally utilized to:

- o obtain more detailed medical findings regarding the impairments,
- o obtain technical or specialized medical information, lab tests, etc., or

- o resolve conflicts or differences in medical findings in the evidence already in file.

The actual determination of the presence of an impairment is made relative to the objective medical evidence available vis-a-vis the Listing of Impairments. Essentially, the functional impact of the impairment and the decision as to whether the impairment constitutes a disability is a legal/administrative one and not a medical decision per se. Thus, a health care provider does not make a decision as to whether his or her patient is disabled, but rather provides an objective assessment of the individual's physical and mental functioning based on signs, symptoms, and laboratory findings. If the listing criteria for an impairment and its severity are met or equalled, the claim will be approved. The claimant's treating provider or DDS CE consultant plays a crucial role in this process by providing pertinent and timely documentation of the impairment(s).

Continuing Disability Review (CDR) of eligibility for SSI benefits is conducted periodically. Under the Social Security Disability Benefits Reform Act of 1984 (P.L. 98-460), new standards for determining continuing eligibility require that medical improvement (with certain exceptions) must be found prior to termination of benefits. The cornerstone of the new CDR evaluation process is the Medical Improvement Review Standard (MIRS). In essence, a beneficiary cannot be removed from the benefit roll unless it can be determined that medical improvement has ocurred since the most recent disability decision and that the child no longer meets or equals the impairment listings. Cases are reviewed at different intervals depending on whether medical improvement (MI) is expected, possible, or not expected:

1. "MI expected" is generally reviewed within 12-18 months of initial entitlement.
2. "MI possible" is reviewed every 3 years.
3. "MI not expected" is reviewed every 5-7 years.

There are three levels of administrative appeal available to SSI applicants and their representatives. If an individual disagrees with an initial decision or a CDR, he or she may file a request for reconsideration within 60 days. The initial determination will then be reviewed by a different adjudicator team in the State DDS agency. If the State agency denies the claim a second time, the applicant can request a hearing before an administrative law judge (ALJ) -- also within 60 days. If the individual is denied benefits by the ALJ, an application for review by the Appeals Council may be filed within 60 days of the decision of the administrative law judge. The Appeals Council also has the authority to deny or grant review of cases.

After exhausting the avenues of administrative appeals, an applicant has the right to file a civil action in the Federal District Court with further appeal to the Court of Appeals and the Supreme Court.

Organizational Structure and Administration

Administration of the SSI program for disabled children involves shared responsibility between state and federal agencies and offices. Applications are received and partially processed by a local social security office (reviews technical eligibility) in conjunction with the State DDS agency (reviews medical eligibility); DDS's are most frequently a part of the State Vocational Rehabilitation Agency. State and Regional SSA offices complete the certification and notification processes. Computation of benefit amounts are made in local social security offices and monthly recurring payments for the SSI program are processed by the regional disbursing centers of the Treasury Department in Birmingham, Alabama. SSA offices of assessment located in the ten (10) regional field offices also independently evaluate State disability

determinations and revise decisions as appropriate based upon documentation in the case file. The activities of these three (3) offices are depicted in the following schemata.

Local and Regional Activities in SSI Case Development

Local Social Security Offices

- Takes application
- Completes nondisability development (financial and other non-medical)
- Splits file - forwards disability portion to State DDS agency
- Prepares and releases technical denial notices

DDS

- Develops medical evidence
- Determines disability
- Prepares and releases disability denial notices

SSA and Regional Disability Quality Branches (DQB)

- Reviews samples of State Disability Determinations (now 65% of new allowances)
- Revises and authorizes selected cases

Notwithstanding the bureaucratic complexity of rule making and administrative policy development, it is believed that the potential for program change should not be underestimated or overlooked. The Associate Commissioner

for the Office of Disability (OD) receives and monitors correspondence received from parent advocacy groups, professional organizations, and members of Congress. In addition, State DDS and regional SSA offices make periodic inquiries for policy clarification and may suggest possible revisions. Another mechanism for policy review and revision is related to the ongoing disability determination review process at both the SSA regional and central office levels. Samples of State DDS decisions are routinely reviewed by medical staff in these offices to assure correct decisions and maintain equity across the nation. As a result of these processes, substantive program issues and concerns continually emerge that can and do lead to an examination of current rules and policy.

Recently, OD has begun a series of initiatives to revise the Adult and Childhood Impairment Listing rules to reflect advances in medical management and to update policies and procedures used to evaluate the severity of particular impairments. Review panels comprised of central office medical and policy staff, regional office and State DDS administrators, representatives of academic and organized medicine, and advocacy groups have been created to study and recommend appropriate changes for several adult and childhood listing sections. At present, the listing sections under review are the Mental Disorders, Musculoskeletal, Respiratory, and Cardiovascular sections.

In addition, studies are conducted by OD to evaluate the impact of current medical criteria as well as proposed listing changes on adjudicative and administrative considerations related to program accuracy, equity, uniformity, and costs of disability policy and the eligibility determination process. Clearly, opportunities for change exist within the program and the agency has demonstrated an openness to those revisions that facilitate and assure implementation of the Title XVI mandate for disabled children.

Current Childhood Beneficiary Profile and Cash Benefit Allowances

It can be seen from Table 1 that program beneficiaries more than doubled during the first three (3) years of operation from 1974 through 1976. Thereafter, the rate of growth went from about 20 percent per year in 1976 to essentially no increase during 1981 and 1982. Thereafter, the increase has been in the range of 5 percent per year. It is interesting to note that it was during the period 1980-1982 that the Title XVI SSI/Disabled Children's Program case management legislation under Section 1615 was rescinded as part of the 1981 Omnibus Reconciliation Act. Although the Title V MCH Block Grant authorizes states to serve disabled children receiving SSI cash benefits, there is no specific earmark for funding or minimum scope and amount of services which must be provided for this child population. The possibility exists that further fulfillment of the Childhood Title XVI mandate and intent may be somewhat dependent on the existence of legislative or regulatory language that would require State Title V Agencies to assure that disabled children from low income families are identified and referred for benefits and assistance through Title XVI.

TABLE 1

Number of blind and disabled children receiving SSI payments, 1974-1985

Year	Blind	Disabled	Total
1974	3,100	67,800	70,900
1975	4,346	123,829	128,175
1976	4,886	148,242	153,128
1977	5,186	170,108	175,214
1978	5,764	191,735	197,499
1979	6,224	205,864	212,088
1980	6,853	221,711	228,564
1981	7,107	222,987	230,094
1982	7,198	221,953	229,151
1983	7,512	228,868	236,380
1984	7,892	240,741	248,633
1985	8,260	257,065	265,325

Table 2 is provided to show the age distribution of childhood beneficiaries. It should be noted that all tables include the childhood population up to 21 years of age. The age group 18 and over is classified as adult disabled children in that medical impairment must, by statute, be evaluated according to the Part A or Adult Listings of Impairment.

TABLE 2

Number and percentage distribution of blind and disabled children by age group receiving SSI payment, by age, December, 1985.*

Age	Blind	Disabled	Total
Total number	8,260	257,065	265,325
Total Percent	100.0	100.0	100.0
Under 5	15.5	15.3	15.3
5-9	14.3	23.9	23.6
10-14	29.8	26.4	26.5
15-17	20.2	19.7	19.7
18 and over	20.2	14.7	14.9

*Estimated from SSI One Percent Sample file.

Table 3 reflects the distribution of SSI children by diagnostic category. Overall, the largest category of children receiving benefits are those with diagnoses of mental disorders, diseases of the nervous system, and congenital anomalies. However, there are significant variations across age groupings in the percentage distribution of these conditions.

TABLE 3

Estimated percent distribution of children receiving SSI payments by age and diagnosis, March 1986.

Diagnostic Group	Under 5	5 - 9	10-14	15-17	18-21*	Total
Neoplasms	3.4	3.6	2.1	2.1	.6	2.7
Endocrine, nutritional, and metabolic diseases	2.5	1.8	1.1	1.3	1.3	1.7
Diseases of the blood and blood-forming organs	2.5	2.4	1.7	1.6	.5	2.0
Mental disorders	21.7	49.3	68.5	74.2	55.5	51.2
Psychoses	.8	2.4	2.8	4.6	4.2	2.6
Nonpsychotic disorders	3.6	4.1	3.6	3.7	2.8	3.6
Retardation	17.3	42.8	62.1	65.9	48.5	45.0
Diseases of:						
Nervous system and sense organs	28.8	24.0	14.6	11.8	31.5	22.1
Nervous system	18.6	15.6	8.9	6.9	10.5	13.0
Eye	4.2	2.3	2.5	2.0	4.2	3.0
Ear and mastoid process	6.0	6.1	3.2	2.9	16.8	6.1
Circulatory system	1.7	.8	.6	.7	.3	.9
Respiratory system	2.2	1.9	1.8	.8	.4	1.6
Digestive system	.6	.1	.1	.2	.2	.3
Genitourinary system	.7	.4	.8	.7	1.1	.7
Musculoskeletal and connective tissue	.8	1.0	1.4	2.1	.9	1.2
Congenital anomalies	21.0	7.5	3.9	1.8	4.5	8.8
Ill-defined conditions	8.6	4.4	1.3	1.3	.4	3.8
Accidents and poisoning	1.1	1.3	1.4	1.1	1.9	1.3
Other	4.6	1.3	.7	.4	.9	1.8
T O T A L	100.0	100.0	100.0	100.0	100.0	100.0

Source: Estimated from the SSI 10-percent file.

* Includes those individuals who are single, not head of a household, and student under age 22.

The SSI program is designed to provide a minimum cash benefit to low income aged, blind, and disabled persons whose combined income and resources are below levels established by the statute. As of January 1, 1986, countable income for the child must be less than $4,032 per year to be elegible for Federal SSI payments. For those children living at home, parental income and resources are deemed available to the child and are considered in determination of the actual cash benefit. For those children requiring long-term hospitalization (beyond 30 days) or institutionalization, parental income is not deemed available to the child and payment level is determined as that of an individual applicant. When an institutionalized child returns to the family home, financial eligibility is again determined in relation to family means.

While the monthly base amount paid to each child is set by the Federal government, there is a statutory clause allowing States to supplement the base. States have broad discretion in supplementing this amount. States can also elect to have their supplementation programs administered by the Federal program. This broad discretion allows States to vary the amount of the supplement by category (aged, blind, disabled), status (individual, couple), living arrangement, etc.

Shown in Table 4 are the major categories and ranges of cash benefits. Although the maximum Federal SSI monthly payment for calendar year 1986 is $336.00, this amount can be reduced to zero assistance by other sources of income (including payment under Title II of the Social Security Act) if the child's countable income exceeds the $4,032 annual limitation. This explains why the average monthly Federal payment of $270.06 is less than the maximum Federal allowance. The overall average of Federal plus State supplement monthly payments as of December, 1985, was $301.36.

TABLE 4

Number and percentage distribution of children receiving SSI payments and average monthly amount received, by type of payment, December, 1985.

Type of Payment	Blind and Disabled Children Number	Percentage	Monthly Benefit Amount
Federal SSI Only	174,408	65.7	270.06
Federal SSI and State Supplement	89,745	33.8	364.75
State Supplement Only	1,172	0.5	81.49
Total	265,325	100.0	301.36

However, it can be seen from Table 5 that almost 62 percent of the children actually receive payments of $336.00 or more per month. Only about 20 percent of SSI beneficiaries receive less than $220.00 per month.

TABLE 5

Percentage distribution of children receiving SSI payments and monthly benefit amount January 1, 1986.*

Monthly Amount	Percentage Blind and Disabled Children
Less than $219	19.5
$220 - $335	18.9
$336 or more	61.6
Total percent	100.0

*Estimated from SSI One Percent Sample File.

Total monthly cash benefits for all SSI disabled child beneficiaries amounted to just under 80 million dollars at the end of calendar year 1985. The annualized cash benefits to these children and their families is currently about one billion dollars.

Implications for Title V State Crippled Children's Services (CCS) Programs and University Affiliated Facilities (UAFs)

While neither State CCS agencies nor UAFs have direct (technical) involvement in implementation of the SSI program, it is believed that there are several aspects of the program where both can have a significant positive influence on a large regulated system such as this one. These include: 1) assuring that children with disabilities are appropriately referred to the SSI program; 2) assuring that comprehensive interdisciplinary medical evaluations for potential beneficiaries are completed in a manner that facilitates correct and equitable adjudication by SSI evaluation teams; 3) assuring that appropriate referrals are made and follow-up conducted for these children so that access to and provision of medical and habilitative services are achieved; and 4) assuring that appropriately trained professionals can be made available to State DDS agencies for CEs and other specialized consultative needs or requests.

Most CCS State agencies and UAF programs have the capacity and willingness to serve as resources for the purposes of disability determinations. Specialty and subspecialty diagnostic and evaluation activities have long been a core activity of Title V related programs and they can be looked to for the provision of expertise in this area. UAF programs have widely acknowledged expertise in the interdisciplinary evaluation and management of children with suspected or actual developmental and chronic disabilities and provide services to thousands of such children annually. We believe the potential exists for further development of creative working arrangements between State DDS agencies, CCS agencies, and UAF programs in assuring timely and quality evaluations of children, especially those with developmental disorders.

Sections 501 and 1615 of the Act provide for the referral of individuals receiving SSI benefits to State agencies administering the State program under

Title V. Prior to the enactment of the Budget Reconciliation Act of 1981, most State CCS programs were responsible for administering the SSI-Disabled Children's case management program legislated under P.L. 94-566. This program mandated the interdisciplinary development and monitoring of an individual service plan (ISP) for each referred child under the age of sixteen. Although the specific requirements of the SSI-DCP are no longer mandated, the program design can serve as a model for assuring continuous and coordinated care for this special population of infants and children under the Title V MCH Block Grant. Several CCS programs have maintained their commitment to their SSI-DCP programs since its inception because of its relevance to the goals and objectives of the Title V mandate. Further, CCS program implementation of coordinating mechanisms with the SSI program is not inconsistent with the Title V mandate of Section 505, 2E of the Social Security law. Results of a recent survey indicate that many state CCS and DDS agencies do, in fact, have ongoing cooperative referral and follow-up arrangements.

Finally, State CCS and UAF programs can serve as advocates for children with medical impairments by assisting Social Security agencies in the following ways. As mentioned above, one potential area for involvement of UAF and CCS programs is by being available resources for initial evaluation and CEs. Secondly, as the SSI medical policy is being studied and revised through the "Notice of Proposed Rule Making" (NPRM) process, CCS and UAF programs are encouraged to communicate their concerns and constructive ideas for improvement to SSA. Lastly, through the development and maintenance of closer formal and informal working relationships among State CCS, UAF, and DDS program staff, the SSI legislative mandate can be well implemented to assist low income families in caring for their disabled children.

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HEALTH-EDUCATION COLLABORATION FOR CHILDREN 0-5

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Introduction

Children who require special support and services from birth have needs that arise from a complex array of biological, environmental and social factors. All children with special needs must have the opportunity to grow and develop to their potential. The universal provision of early comprehensive, interdisciplinary, community-based, and high quality intervention services for these children and their families offers great promise. Increasing evidence suggests:

- Improvement of long-term outcomes of children and families including preparation for school, personal life, world of work, and life in the community;
- prevention and/or reduction in crime, poverty, malnutrition, violence, substance abuse, and need for more costly and intensive services;
- reduced institutionalization;
- growth of active parent involvement and empowerment;
- more opportunities to participate in the mainstream of society; and,
- improvement in technologies of bio-medicine, measurement and intervention.

Additionally, 30 states now have laws that authorize more and better services to these youngsters below school age and, in some states, additional monies have been appropriated. Standards and regulations prevail in many places along with licensure and certification of competent personnel. However, the universality of these desirable services is far from a reality in our nation.

While progress has been made, many obstacles and challenges remain to the

achievement of universal and full services for young children with special needs:

- high rates of poverty, infant mortality, and a growing minority population along with increases in single-parent households and teenage parents;
- numbers and definition of the target population(s) eligible to receive services;
- determination of comprehensive services and the related components;
- delineation of philosophy and expectations for early intervention services;
- need for more money;
- fragmentation of services among federal, state, regional and local agencies and other service organizations;
- struggles for control of services;
- lack of stable and continuous services to children;
- deficiencies in trained personnel;
- inadequate child-find and reporting systems;
- difficulty in adaptation services to geographic factors--e.g., urban, rural, or migrant; and
- delineation of the continuum of service locations -- hospital-based, home-based, and community based -- in the least restrictive manner.

Given these barriers, challenges, and complexities, professionals must galvanize their sense of common purpose. The participation of both the health and educational systems in the process is essential.

Background

In planning early intervention services for young children with special needs and their families it is necessary to identify the target population to be served. Since the 1920's the health system has provided medical as well as early intervention services to children with biological and developmental problems identified at birth or during the first few years of life. The health

system has typically been the first point of professional contact for families of very young children with these kinds of special needs. Typically health departments and practicing pediatricians have been involved with children at risk for or evidencing medical and developmental problems. A range of prenatal and perinatal factors contribute to problems identified by the health system at birth including maternal practices such as the use of teratogens, maternal health (i.e., rubbella cytomegaloviruses, toxoplasmosis, AIDS), labor and delivery events, low birth weight, and genetic conditions. Health professionals have sought to provide therapeutic alternatives to ameliorate problems before they become disabling, thus taking a prevention focus.

Since the 1960's, the education system has taken an interest in special needs children below school age. These children have included those with recognizable handicaps and those with developmental delays. Recognizing the importance of early identification of education problems, educators seek to identify young children who can benefit from programs that facilitate intellectual, emotional, physical, social and language development and to guarantee access of children with special educational needs to publicly sponsored education and related services from the time that they are born. Family programming, individual planning, and integration experiences have emerged through this system.

While the goals of the health and education systems are not totally congruent, both are committed to serving young children with "developmental" needs and both recognize the importance of early intervention. In planning early intervention services between health and education, at minimum the following groups of children should be considered:

1) Infants with discernible handicaps at the time of birth;

2) Infants who have conditions or diseases that, when recognized at birth by biochemical or other means, can lead to prevention of handicapping

conditions later in life;

3) infants whose births are associated with maternal (social or biologic) factors or infant (biologic) factors that place them at high risk for the eventual development of a handicapping condition; and

4) infants who exhibit a delayed or otherwise abnormal development course whose births are not associated with social or biologic factors that place them at high risk for developing handicapping conditions (Healy, Keesee, and Smith, 1985).

The group of children less clearly specified and for whom services are less well defined are those children at risk for later developmental and educational problems because of social and evironmental factors. This very important group will not be addressed in this paper since their needs cannot be sufficiently discussed within the space limitations.

Developing Collaboration Between Health and Education

In developing collaborative strategies for early intervention services between the health and education system, the needs of the children and their families must be held paramount. The goals of early intervention must be based on sound developmental principles, recognize the importance of the emotional well being of the child and family, and firmly incorporate the concepts of family support. Parents of all very young children must find ways to adapt to their child's needs and ways to love, stimulate, enjoy and protect their children. Support systems such as family and friends, pediatricians, nurses, and educators are the natural resources to whom families turn for support in their parenting roles. For parents of children who have special needs from birth, their natural support networks are usually stressed by lack of

understanding of the problem, fear, and reluctance to accept additional burdens. Given both the potential strengths and limitations of the natural support networks of families, the health and education systems should collaborate to develop early intervention services that build and enhance that which is available in the natural ecology, both within the family's support network and in the existing community.

With these premises, it is useful to examine the types of services that are helpful to families of children with special needs, keeping in mind family differences and, naturally, available supports. For families, there are those services that address the particular needs of the child and the condition as well as the total family. These service needs will vary based on the individual differences among families and the parameters of the condition itself. Examples of such services might include screening, evaluation, and intervention services; genetic couseling; financial counseling; parent groups; transportation; legal services; parent training; sibling support groups; day care; respite care; homemaking services; and assistance in obtaining equipment. Specific services such as these might readily be seen as components of either the health or education service system. History, local resources, and other factors in the ecology will influence which agency or provider sponsors these activities and how they are coordinated. In addition to these types of services, but especially important to families, are what can be called enabling services -- those services that make it possible for families to optimally utilize needed services. Identification and referral systems and case management systems are examples of such enabling services. These enabling services must be well coordinated in the system for families to access and utilize services available. Frequently these are the least well developed by either health or education and are very poorly coordinated across health and educational systems. By their very nature these enabling services should be planned and implemented in a

collaborative way.

Beyond Health and Education

In reality the issues in developing and implementing services for young children and their families extend beyond the relationship between health and education. During the last decade, the number of programs serving young handicapped children and their families has increased. This growth reflects an increase in the number of young handicapped children identified and served. However, while the number of programs and the number of children served has grown, there has been slow growth in program coordination and integration and in adequate procedures for sharing information about proven models and practices.

A number of federal programs have been established to improve services to young handicapped children and their families. Many of these federally sponsored programs have sought to become coordinated, comprehensive, and integrated with state and local human services systems. The federal programs include:

- Social Security Act (Crippled Children's Services; Maternal and Child Health Services; SSI, EPSDT; and Title XX)
- Head Start
- EHA including P.L. 94-142 and its HCEEP and Preschool Incentive Grants
- Chapter 1 and P.L. 89-313
- Child Nutrition Act and WIC Program
- Developmental Disabilities
- Social Services

Regrettably, conflicting national agency regulations and requirements and minimal program coordination within individual federal agencies have, in the

end, diluted state and local efforts to coordinate planning and delivery of services. Also, the various model state and community programs which have been developed within individual agencies are seldom shared.

The Sixth Annual Report to Congress on the Implementation of P.L. 94-142 (1984) by the U.S. Department of Education suggests that federal programs, such as Maternal and Child Health, Developmental Disabilities, and Education have made progress toward our nation's goal of integrated services to all young handicapped children. While much has been achieved, the full potential and integration of these efforts has not been realized.

Politicians, advocates, parents, and representatives from public and private agencies pushed hard for new federal legislation to accomplish this goal. At a 1983 House Subcommittee on Select Education hearing on the reauthorization of the EHA amendments, OSERS assistant secretary Madeleine Will testified: "There still remain gaps as well as overlaps in what is envisioned to be a comprehensive service delivery system." A consensus emerged that a re-directed national initiative was needed.

Legislative Actions: Implications for the Health Care System

P.L. 98-199

In 1983, Congress acknowledged that there was a need for national improvement in services to young handicapped children and their families. The Congress further believed that the responsibility to bring about needed changes must be shared by a partnership of local, state, and federal leaders. The federal government should serve as a catalyst to this initiative by providing some guidance, resources, technical assistance, research, and access to diverse experimental and innovative projects.

P.L. 98-199, approved by Congress and signed into law on December 3, 1983,

established several new opportunities for young children. One particular opportunity was to expand the quality and quantity of planned, comprehensive, and coordinated services to young handicapped children and their families in every state, territory, and the District of Columbia. The new laws called for cooperative action from federal, state, and local authorities, advocates, private-sector service providers, professionals, and parents. P.L. 98-199 allowed states to use preschool incentive grant money for children from birth, stimulated the involvement of parents in state-level planning, encouraged interagency collaborations at the state and local levels, and encouraged states to support the training of infant care givers. In short, P.L. 98-199 provided a framework, monetary resources, and a plan for a partnership to undertake an initiative that stresses the concept of comprehensive service delivery systems for all young handicapped children and their families. Professionals and parents working together should find it easier to identify needs, to pinpoint fragmentation (gaps and overlaps) in current services, and to make plans for future services.

The State Grant Program recognized that planning takes time and resources. Up to eight years of federal funding was to be available, if needed, for states to undertake successfully this challenging and complex task. It authorized three phases of grant activity with respect to comprehensive service delivery systems for children birth through 5 years of age:

> "(A) PLANNING GRANT. A grant for a maximum of two years for the purpose of assessing needs within the state and establishing a procedure and design for the development of a state plan which includes parent participation and training of professionals and others."
>
> "(B) DEVELOPMENT GRANT. A grant for a maximum of three years for the purpose of developing a comprehensive state plan and gaining approval of

this plan from the state board of education, the commissioner of education, or other designated official of the appropriate state agency."

"(C) IMPLEMENTATION GRANT. A grant for a maximum of three years for the purpose of implementing and evaluating the comprehensive state plan."

These three grant phases were to function in sequence, leading eventually to an early childhood state plan for a comprehensive service delivery system.

Collaboration between health and education related to 98-199 took many forms. It was evidenced through structural relationships, community focused activities, tracking systems and case management plans. In the state of Washington several planning groups merged to form a Birth to 6 Committee; in Utah the health department was the recipient of the 98-199 funds; in Illinois a series of multiagency, multidisciplinary pilot programs for community based, comprehensive services to young children and families was developed; in Maine the Interdepartmental Coordinating Committee for Preschool Handicapped Children planned to extend the services of all of its 16 local coordinating service sites to birth; in a number of states (Oklahoma, Louisiana, Virginia, Idaho, and Hawaii) community forums or listening conferences involved health, education and other professionals, and parents to gather input about the problems.

P.L. 99-457

On October 8, 1986, Congress enacted P.L. 99-457, amendments to the Education of the Handicapped Act, which will have a major impact on the collaboration between health and education agencies for young children. This law builds on the concepts in P.L. 98-199 and now replaces it. P.L. 99-457 includes numerous initiatives pertaining to young children with special needs and their families. It provides incentives to States to serve an estimated additional 70,000 handicapped children, ages 3 through 5, who currently are not now being served (260,000 children currently are being provided services), and creates a new discretionary program to address the special needs of handicapped

infants and toddlers (birth through age two) and their families. Under the Act, after four years, each State -- if it wants to continue receiving federal financial assistance under the birth-2 and 3-5 programs -- must have in place among other things a policy to provide appropriate early intervention services to all handicapped infants and toddlers in the State.

Most notable in the new law is the portion for infants and toddlers. P.L. 99-457 creates a new discretionary program to assist states to plan, develop, and implement a statewide, comprehensive, coordinated multidisciplinary interagency program for very young handicapped children, birth through 2 years of age. Minimum system components include such items as:

- o a definition for developmental delay
- o a timetable for services
- o an individualized family service plan and case management
- o a child find and referral system
- o a public awareness program
- o a system of comprehensive personnel development, and
- o a lead agency and interagency Coordinating Council designated by the Governor.

Grants will be made to states by the U.S. Department of Education.

Congress, through P.L. 99-457 and all of its pieces, wishes to expand the benefits of early intervention to more children and families. Some observers have called this new legislation "a Head Start program for handicapped infants and preschoolers." As with most change, however, there are still some outstanding issues to be resolved:

- o Methods of informing new parents of available services need very careful attention; experienced parents should be part of the initial contact. Current models such as Pilot Parents exist.
- o Integration of the children and their parents must be the #1 priority

from the beginning. This is an area where pediatricians are in an ideal position to assume leadership since they themselves conduct "integrated" practices in treating children.

- There is a need for adequate safeguards to insure that the Individual Family Service Plan (IFSP) serves to support families rather than serves as a disruptive force. The following are some specific concerns:
  - -- privacy, confidentiality, use and protection of records,
  - -- dangers of wasteful time and effort in the process of assessment and developing the plan, and
  - -- role of the parents. They must be accepted and supported as leaders of the multi-disciplinary team.
- The system should be responsive to family differences in terms of what it requires in the team, e.g., number of evaluations, repeated evaluations.
- "Case Manager" is a multilevel issue. How do we support parents as the managers of the care of their children? How do we "manage" a disorganized system of care?
- The Least Restrictive Environment (LRE) mandate must be strenthened. It is important for parents to start out integrated with other parents.
- The definition of health and medical care. What is or isn't discussed in the law must be addressed.
- Serving children who are in hospitals for extended years is not clearly specified. Language in the regulations to facilitate this is needed.
- How the Interagency Council is formed, the selection of a lead agency and empowering equal partners are important process issues. The role of health as the lead agency because of its historic and current

responsibilities must be considered.

- Birth-2 and 3-5 programs should not be fragmented; the role of the Interagency Council could cross over.
- The penalty for not participating in 3-5 programs could be cutting off an important national resource in developing innovative programs. There may be states where there are not good statewide systems, but where exemplary programs may emerge through incentive and discretionary grants which would be curtailed as the penalty.
- The issue of accountability is critical. If a service is written in a service plan, who is required to give it? Who will pay for it?

Currently regulations are being developed by the U.S. Department of Education through which some of these issues may be resolved.

Despite the number of issues raised, enthusiasm for the new law far outweighs the concerns. Diane Crutcher of the National Down Syndrome Congress has summed it up best. "Although there is never perfect legislation, we, as parents, are quite pleased with the fact that this legislation has been enacted. It recognizes a vital need for children with disabilities and their families. We have many concerns about the legislation and how it will be effected on a local level but the dramatic statement it makes relative to the importance of services and the rights of children and families wins a battle we have been fighting for some time. So for those involved in the writing and passing of the legislation, we thank you."

Other Initiatives: Health and Education Collaborations

Beyond Public Law 98-199 and P.L. 99-457, there have been a number of federal initiatives that have highlighted the importance of collaboration between health and education for services to young children from the U.S.

Department of Education as well as the U.S. Department of Health and Human Services. The following is a sample of such efforts:

The Handicapped Children's Early Education Program (HCEEP) of the U.S. Department of Education supports diverse and innovative approaches (services) to young handicapped children and their families. Several projects specifically relate to collaboration between health and education:

- The Facilitative Environments Encouraging Development (FEED) Project of Hunter College in New York City. Junior high school students receive instruction in the nature of normal and delayed development. They work with young handicapped and nonhandicapped children in preschool and health-care facilities.
- The Parent-Infant Growth, Advocacy and Planning Project of the Department of Pediatrics/Neonatology at the University of New Mexico. Premature and critically ill infants and their families are involved in this project which applies an integrated medical/developmental intervention model to maximize their developmental potential.
- Children in Hospitals Projects at the UCLA Center for Health Sciences in Los Angeles. This project helps hospitalized chronically ill children and their parents develop healthy interactions, promotes optimal cognitive and emotional growth, and instills confidence in parents planning for their children's total needs.
- Infant Interagency Network Through Accessing Computer Technology Project of San Diego State University, California. Children with any handicapping condition, birth to age 3 years, and their families have access through referral to a computerized directory of interagency services. The project also provides some direct short-term assessment and intervention.

Project START and TADS at the Frank Porter Graham Child Development Center provide technical assistance to states in relation to their state plans for comprehensive service delivery.

Project NEXUS at the University of Kansas is a technical assistance project for developing community-based programs for young children with special needs and their families. This project is developing a manual and related materials to help local communities develop a plan of action for comprehensive services.

Project BRIDGE, offered by the American Academy of Pediatrics, is the first national education program designed specifically to help early intervention teams improve their functioning and decision-making skills, while demonstrating the state-of-the-art in services for young disabled children and their families.

Special Projects of Regional and National Significance (SPRANS) in the Division of Maternal and Child Health, Department of Health and Human Services, have targeted service coordination strategies for children with special needs. Several specific projects particularly focus on health and education collaboration for young children. Examples of these include:

- Project Zero to Three at the National Center for Clinical Infant Programs works with 15 states bringing together health, education, and other professionals and parents to address service issues for children with special needs from birth to three years of age. States have focused on issues such as tracking, legislation, and program evaluation and share expertise with each other.
- The National Center for Networking Community Based Services at Georgetown University Child Development Center has been jointly supported by health, education and other agencies to share, disseminate, and coordinate expertise on community based services with 35 states. Many states have focused on the health/education collaboration issues for children from birth to five.

- A Community Collaboration Approach for Developing Early Intervention Services in Oklahoma. The University Affiliated Center in Texas, in conjunction with the Oklahoma Department of Health, is developing and implementing collaboration strategies for children 0-5 in at least 5 communities in the state. The staffing and thrust of this project represents a combined effort of health and education professionals and agencies. This is an exemplary project of a UAF working closely with a state servie system to improve community based services through coordination and collaboration.

Implications for Title V and UAFs

While UAFs have long provided excellent interdisciplinary training in early intervention, they have been less involved in training that relates to the state's coordinated service delivery systems. UAFs have a wealth of professional expertise that could be directed toward improving the coordination capabilities at both the community and state level within their regions. UAFs developed some of the earliest intervention models and have a wealth of expertise in the early intervention area. As state policy and planning groups gather to consider the ways in which services to young children should be delivered and the respective roles of health and education, the UAF can be an important resource both in service content and in facilitating the process of working groups. With the current thrust of services for children 0-5, UAFs have the opportunity to expand their role in the coordination of services between health and education.

Research in this area is sparse and is another fertile arena for UAFs. As states develop their comprehensive systems, UAFs can collaborate with state and

local agency personnel to plan and conduct pertinent research on mutually agreed upon topics.

As communities work toward establishing better community based services, again the UAFs can provide exemplary leadership and skills in establishing service programs. UAFs must continue to evolve models of service for young children with special needs across health, education and other disciplines that will be useful for communities to replicate.

UAFs have been an example of training settings where health and education professionals have had to forge collaborative programs. They provide a unique opportunity for professionals to train under the influence of other disciplines — health and education, respectively. Because of their interdisciplinary context UAFs are uniquely qualified to train future professionals in policy development for young children with special needs. This is not a training area that has been developed in the UAF curriculum as extensively as it might be. In addition UAFs should be training health and education professionals in system building and in strategies for coordination. Early attitude shaping of professionals can be a potent contribution toward system change.

With respect to Public Law 99-457 there is a need for a close working relationship between Title V programs, the U.S. Department of Education and UAFs. The involvement of health professionals in the P.L. 99-457 advisory groups is critical for a careful blending of services between MCH/CC and other programs. MCH/CC programs can be instrumental in involving private sector physicians in the planning and implementation of comprehensive services for young children with special needs, in involving the pediatrician with the Individualized Family Service Plan (IFSP), and in addressing such problems as sharing of records and information between health and education systems. The expertise, information, and skills of the health programs can serve as a strong base for newer integrated and coordinated programs and strategies. MCH/CC

programs, with their long history of service provision to this population, also have an important role to play in quality assurance of services to young children and their families. This quality assurance role is a vital one as services proliferate and expand.

Most importantly, Title V programs and UAFs can continue to serve as advocates for families as they negotiate the maze of services, professionals and jargon. All of us together have the paramount responsibility to see that the policies, services, training and research we conduct related to young children with special needs is family and child centered.

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CHILD ABUSE AND DEVELOPMENTAL DISABILITIES

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Introduction

It is a seeming irony that such a terrible subject as child abuse should prompt so many different authorities to desire to "own" it. The state of disagreement and turmoil which characterizes the field led to Zigler's self-admitted pessimism in his May, 1976, address at the Meyer Children's Rehabilitation Institute (UAF) in Omaha. Having headed the U.S. Office for Child Development, Zigler was well aware that efforts to bring order were confronted by lack of coordination and territorial wrangling. He criticized most preventive efforts as being secondary, or after-the-fact. He also bemoaned the expense created by the attitude that only professional workers could resolve these issues, stating that this line of thought was an approach which we as a society could ill afford. However, in a more positive and constructive tone, he called for a logical and orderly primary preventive approach comprised of six avenues:

1) Invigorated research and data collection
2) Increased efforts for family planning
3) Widespread implementation of education for parenthood
4) Massive effort to reduce prematurity
5) Increase in the availability of homemaking services
6) Immediate increase in the availability of child care

These were reiterated four years later in a jointly edited book (Gerbner, Ross & Zigler, 1980). Current reflection upon the field of child abuse, reveals that these six deserve renewed consideration.

Invigorated Research and Data Collection

Much work has been done in this area. However, problems persist with what often become piece-meal efforts, lacking commonality of focus or even the foundation of a broadly accepted definition of child abuse. Many writers and discussants have responded to such criticism by cautiously reciting the legal definition of the United States Child Abuse Prevention and Treatment Act of 1973: "the physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a child under the age of eighteen by a person who is responsible for the child's welfare, under circumstances which indicate that the child's health or welfare is harmed or threatened thereby." They then usually follow with the inclusion of phrases such as "omissions as well as commissions" or some other favored wording or variation on the theme. The net effect is that there currently remains only rather loose agreement on areas of concern rather than any firm operational definition.

The problem of data collection itself was administratively assigned to the National Center on Child Abuse and Neglect, which undertook extensive efforts to coordinate research and data collection. However, the designation was based on inaccurate estimates of the cost of such endeavors, either in the work force or fiscal backing necessary. The real extent of what was needed to bring so many diversified state, local government, and private agencies into some sort of coordinated system was sadly underestimated. This in turn led to lack of common concern and contributed to the conclusion of Newberger, Newberger, and Hampton (1983) that "the inadequate understanding of the state of knowledge promoted by the anxiety which child abuse stimulated in all of us, is translated to recommendations for intervention, many of which are heavy handed, unspecific and insensitive, and some of which are downright harmful."

Newberger, Newberger and Hampton (1983) also categorized five groups of "unitary theories" of causation, the first of which, "psychoanalytic" or perhaps later "psychopathological," seems to evolve from symptomatic releases of violence which might be difficult to distinguish from their later "socially learned" violence. However, the issue of family violence in recent years seems to have become a uniquely established focus in and of itself. In fact, both the Attorney General's Task Force (1984) and the Surgeon General's Workshop (1986) focused upon domestic violence. Zigler (1976), in the lecture cited above, decried the generalized societal acceptance of violence as being evidence of current unwillingness to realistically confront the underlying issues of child abuse. Early derivation of this domestic violence focus stemmed from such works as that of Johnson and Morse (1968), reviewing issues of parental choice of punishment. Gil (1970, 1975) and Gelles (1980) advanced the perspective over the concern to all forms of violence. This in turn led to considering the presence of domestic violence (with its potential resultant child injury) as an independent variable which merits a classificatory categorization of its own.

A more concrete physical injury perspective, including the concern over possible resulting brain damage or physical developmental delay, was voiced in the earliest "battered child" writings of Kempe, Silverman, Steele, Droegmuller and Silver (1962), Berenberg (1969), Alexander (1979), and Solomons (1979). Later these evolved into etiological considerations such as those of Nelson (1978) or Diamond and Jaudes (1983) in their reviews of the proportion of abused children within the cerebral palsy population.

Another important focus in searching for causality has been the review of "risk factors." Leventhal (1981) provides an outstanding demonstration in that none of the 19 studies he critiqued meets all seven of the criteria postulated as necessary for controlled comparison. In this stringent analysis, he showed that

prematurity or low birth weight alone should not be judged as major contributing variables to such risk. Adolescent parenting, however, appears to be the most troublesome contributing variable, being confirmed in almost all studies as highly significant. This was true even when problems with controls or contrast groups were present. The risk of adolescent parenting is further borne out in Elster, McAnarney and Lamb (1983), Smolen, Miller, O'Neil and Lawless (1984), and Ventura and Hendershot (1984).

More concentrated focus on issues such as bonding, attachment formation, and the potential of a troubled parent-child relationship are found in Frodi, Lamb, Leavit, Donovan, Neff and Sherry (1978), Friedrich (1979), Blacher and Meyers (1983), Schneider-Rosen, Braumwald, Carlson and Cicchetti (1985). Friedrich and Boriskin (1976) concentrated on child variables as being disruptive of the attachment process, claiming that interaction theory should not be limited to questioning only the parental psychopathology or parental trait weakness. Frodi et al. (1978) honed in on the issues of child facial features and degree of crying which could interfere in the attachment process. These more basic research efforts serve to broaden the frame of reference essential for more comprehensive understanding of the problem and for deriving more constructive approaches to correcting some malfunctioning parent-child relationships.

At further consideration are the social issues raised by the Zigler lecture (1976), which were explored more broadly by the Interagency Task Force on Prevention (Morocco, 1984). Further emphasis by Gelles, (1979), Newberger and Newberger (1982), Newberger, Newberger and Hampton (1983), and Meier (1985) reveal that this focus also must be given the attention it deserves.

Following the logic of the preceding literature review, the author wishes to suggest the following categories to organize data collection:

(A) Approaches to curtailing or resolving Family Violence

(1) crisis intervention; and
(2) prevention (one of the key present issues).

(B) Physical injury (possibly an outcome of violence)

(1) intentionally inflicted;
(2) "questionably" accidental; and
(3) sexual abuse (since any sexual involvement of a child by an adult is a violation to the degree that the harm inflicted upon the child can only be comparable to other forms of overt violence).

(C) AT-RISK Considerations

(1) prematurity (coupled at times with either social problems or family instability);
(2) adolescent parenting;
(3) bonding/attachment problems;
(4) failure to thrive; and
(5) incompetent, inadequate, or incapacitated parents.

(D) Social issues requiring special surveillance

(1) unemployment;
(2) impoverishment;
(3) isolation or remoteness from sources of emotional and extended familial support;
(4) parental personal weaknesses and/or habitual substance abuse; and
(5) other high stress situations.

Prevention Issues

Increased Efforts for Family Planning: This objective stems from a common sense derivation: an unwanted pregnancy is one likely to result in a resented, rejected, or vulnerable child. But what would be considered valid statistical support for such a logical hypothesis? The variable does not easily submit to reliable measurement. Difficulties arise among disparate agencies due to intense disagreement, if not open hostility, involved in approaching this subject. There is a considerable difference of opinion as to what constitutes needs-assessment data in this area. Yet there seems to be fairly uniform hypothetical agreement that an unwanted child is a ready target for child abuse,

and for this reason the issue is readily counted as being important in any child abuse preventive approach.

Widespread Implementation of Education for Parenthood: Again the issue is how? What effective models are worthy of replication? How might they be expanded? Are public schools ready or willing to accept this intrusion into the social or familial realm as being part of their responsibility? How can educational institutions equip themselves to resolve some of the resulting disagreement and dissension resulting from the pluralistic perspectives of our society?

A Boston model program designed by Deborah Prothrow-Stith (1986) is worthy of further consideration. Her ten week modular course, offered in the Boston public schools, focuses mainly upon health content, but stresses concern over issues of violence, intimacy, sexuality, human caring, understanding the human body, the full meaning of having a dependent child, and the broader involvement in family relationships. The content of this model program has many merits, including some concentration upon wishful thinking and common folklore myths. It avoids some of the pitfalls of traditional "home and the family" housekeeping courses which have little appeal or value to here-and-now adolescents. It also is interdisciplinary, offering the availability of approachable medical authorities who can reach out to provide an essential knowledge base. Also, as team members, they often supply appropriate personal introduction, guidance, or direction to resource personnel who might promote other, more therapeutically-oriented, helping relationships.

Massive Effort to Reduce Prematurity: Leventhal (1981) opens questioning pertaining to any direct causal contribution of prematurity to child rejection or abuse. Yet there are differences between premature and normal infants. Again, on a theoretical or a priori basis, it would seem that smaller and less

developed premature infants have more chance of encountering problems which make them more difficult to parent or care for and which may lead to their being less readily "bondable" babies.

Zigler's (1976) last two programmatic recommendations are an increase in the availability of homemaking services and an immediate increase of the availability of child care. Both are recognizable needs in all human service areas. However, they are particularly important in the developmental disabilities field, where each is necessary for the promotion of normalization efforts and the maintenance in the community of individuals who are developmentally handicapped. These were derived from what Zigler called "efforts to beef up our nation's general social service programs." It should be recognized that such programs are essential components of the Individualized Service Plan for every handicapped individual. The "beefing up" of these programs should be interpreted as assuring that they become more readily accessible, and that sufficient support personnel are available to make them workable and efficient. However, it also should be recognized that the handicapped client is already required to have an Individualized Service Plan. Each plan is expected to have the input of "qualified" professionals who provide the guidance and overview to make goals obtainable and objectives workable. It is at this point that some disagreement is found with Zigler's complaint that society cannot afford professionals in this area of endeavor. On the contrary, it would seem that our society cannot afford to waste effort on programs which do not have sound professional guidance and direction to assure their effectiveness. The affected individuals cannot afford the loss of direction or the loss of progress which the resultant confusion might cause. Granted, sufficient support staff are needed for carrying out plans and making programs work. But it cannot be denied that well-trained and efficient professional team guidance can make the difference between wasted efforts and beneficial returns to both society and the individuals

needing help. This is especially true when handicapped individuals are involved or where individualized service plans are linked with therapeutic or training efforts.

Linking Child Abuse and Disability

It must be acknowledged that preventive endeavors reflect a more theoretical approach. Actual clinical and treatment statistics encounter many sorts of reporting problems. Almost from the inception of the battered child concept (Kempe et al., 1962), some relationship between child abuse and developmental delay was recognized. The logic of that relationship has been discussed elsewhere by this author (Cushna, 1979). However, the debate over causality continues to be voiced regardless of the opinion of many viewing that matter as a "first the chicken or the egg" type of argument (Meier and Sloan, 1984). Any accurate comparison of numbers of children within these classifications remains open to question.

Friedrich and Boriskin (1976) reviewed reports of high frequency of all types of handicapping conditions among abused children, finding a disproportionately high representation. However, any difference between the reported frequency of child abuse among handicapped children as compared to the "normal" population has never been established as significant. In addition, the degree of disability of the various populations such as those reviewed by Friedrich and Boriskin (1976) was not always carefully delineated. Certainly everyone who looks at specific disability groups has recognized some presence of child abuse cases. This has led to considerable speculation regarding the cause-effect relationship. It especially becomes alarming where the effects of a damaged brain may cause organic impairment such as cerebral palsy or mental

handicapping condition caused by the child abuse injuries or whether the condition was the determining variable which led to the targeting of this particular child (perhaps out of a sibship) for this type of victimization. In viewing the cerebral palsy population, especially in England (Nelson, 1978; Diamond & Jaudes, 1983), the high frequency is again noted, as are the factors of family stress, unemployment, impoverishment, remoteness from sources of external support, isolation, and personal weaknesses, substance abuse, or incompetence on the part of the parents.

Able and Healy (1985) reviewed the 1984 Iowa Care and Protection statistics, and found that only 1% of this population had any question of developmental delay or mental retardation. They felt that the data may have been inaccurate. And, in fact, collecting data of this sort incorporates all sorts of recorder bias, plus the potential for non-recording due to the fact that the handicapping problem may not be specified and consequently not focused upon. But the possibility also remains of the frequency being far below what may have been expected, and consequently both handicapped and "normal" groups sharing common norms.

The real issue is <u>not</u> what came first <u>nor</u> what is causal, but what to do about the population that actuarial data reveal is there. Many children are both developmentally delayed as well as abused, neglected or victimized. To paraphrase Zigler (1976), it matters not whether there are 1,000 or 1,000,000, this "constitutes a social problem." Consequently, what special preventive, precautionary measures need to be instituted? It should be self-evident that more effective therapeutic or remedial programs need to be available at the present time.

Demonstration Projects

The UAFs are well established training programs already involved in a

Demonstration Projects

The UAFs are well established training programs already involved in a variety of exemplary services for handicapped individuals. They have been extensively involved in the area of child abuse. UAFs have responded generally in four directions to child abuse issues. The first has been (1) preparing professional personnel to respond more effectively to child abuse problems. Secondly there have been a number of projects (2) bolstering Care and Protection agencies. This was Mark Souther's (1984) initial effort in West Virginia and Judy Powell's (1986) work in Tennessee. Efforts in Massachusetts involved a broad training program with the state Department of Social Services, with numerous inservice training sessions held for local catchment area service personnel and also regional workshops. (3) Broader agency support has been extended to groups such as Head Start and the Local Education Agencies or Public Schools, although with the latter an issue often arises over school systems being ready to address issues considered to be family or "social" problems. UAFs also have become involved in (4) other clinical and legal training (often in juvenile or family courts) regarding child abuse and care and protection topics.

In terms of broader agency support, many UAFs have worked intensively with local Head Start efforts. This is a logical training investment in that many of the precipitating problems recognized as being associated with child abuse, such as economic deprivation, personal isolation, and family stress, appear frequently in the Head Start population. At the start of the Boston UAF Child Abuse project, regional training was provided for over 1,000 Head Start workers across New England at seven different Regional Access Project (RAP) 2-day workshops in 1980-81. These efforts subsequently contributed to the evolution of an Interagency Task Force, bringing together UAFs from five different

national regions with their respective Head Start RAPs. Backed by the Department of Education, the Administration on Developmental Disabilities, and the Administration for Children, Youth and Families, this Interagency Task Force represented five areas where exemplary Head Start/UAF collaboration had been demonstrated.

These were: Georgetown Child Development Center (UAF) in Washington D.C. (where the RAP is operated within the UAF); the Crippled Children's Division Child Development and Rehabilitation Center (UAF), Portland, Oregon; the Center for Developmental and Learning Disorders (UAF), Chapel Hill, North Carolina; the Kansas University Affiliated Facility, Kansas City, Kansas; and the Developmental Evaluation Clinic, Boston, Massachusetts. The mandate to the Task Force was to demonstrate services which could contribute to preventing abuse and neglect of handicapped children enrolled in Head Start; to adopt these several approaches and materials for use by public schools; and to ease the transition of handicapped Head Start students into public school programs.

Unfortunately, this rather extensive mandate was compromised by major budget limitations. These in turn restricted project design to a diminished scale, carried out with minimal staff over the first six months of 1984. Geographic differences also produced considerable diversity in types of school affiliations and methods of evaluating outcome. Even with this diversity, the projects were able to reflect the current state of the art of child abuse prevention in several dimensions.

The relative strengths and limitations of the five approaches, detailed information for replication, and suggestions for future development of preventive approaches can be found in the final report (Morocco, 1984). Each project had some unique and valuable contribution. As Morocco (1984) described, these followed a spectrum from training support workers specialized in bolstering families at times of pressure and stress, to sensitizing and skill-building

among community professionals to assist families where the potential for abuse was greatest.

The Boston contribution to the UAF/RAP Interagency Project will be discussed here in more detail since this was more intimately linked to the child abuse effort and other projects to be discussed shortly. The Boston project actually took place in a satellite city within a 30-mile radius of the UAF. Because of the limited fiscal backing, a choice was made among several alternate sites where a model pilot project might be effective within the six month framework. The site chosen was a former mill town where unemployment was in the upper tenth percentile for the state. Also, there was both a high degree of reported child abuse and a demonstrated need for Head Start service in the area. By Massachusetts' standards, the public school special education department would have been considered "weak." In fact, at this time, although the Massachusetts special education law mandating individualized mainstream education had been in effect for ten years, this school system still maintained an essentially segregated (isolated) building for the bulk of their special education students.

The Boston UAF/RAP area project developed objectives in three areas. Within the public school, two series of inservice programs were conducted. The staff working with handicapped children received active consultation over this period regarding referral opportunities and interdisciplinary programming. Two didactic full-day workshops were conducted, and selected staff were invited to the UAF for reviewing comparative opportunities for educational planning and case discussions. Also, a series of inservice programs was held for teacher aides throughout the system. This was the first teacher aide inservice for that school system. In the Head Start component, both center-based and home-visit staff were trained in the recommended child abuse curriculum. Also, a concen-

trated training program was designed for a group of specialized aides who could provide supplemental support services to at-risk families. These "support aides" were trained to provide non-judgmental listening and to assist parents in resolving stress and overcoming personal isolation. Thus, a model of direct family support evolved, emphasizing the effects of the Head Start family workers receiving special training to carry out more preventive roles. The social service coordinator for each Head Start program participated fully in this endeavor. Their alliance assured the continuation of this focus after the pilot project period was completed. The main contribution of the Boston area project, however, was in bringing Head Start and the public school system together, and promoting their continued working together at the termination of the pilot project.

Results of the Boston Care and Protection Project

From a clinical viewpoint, Boston Children's Hospital undertook a 3-year project with the Massachusetts Department of Social Services supported, in part, by the National Center for Child Abuse and Neglect. Data from the first 250 cases were compiled and examined to review the significance of the services provided. Although the heaviest concentration (over 30%) of the children were referred near the time of entry to school, there were children referred in all age groups.

Table 1

DEVELOPMENTAL DISABILITIES AND CHILD ABUSE PROJECT

First 250 Children Evaluated in Boston

Age of Children Evaluated (in Years)

Years	0 - 2	3 - 4	5 - 10	11 - 14	over 14
#	62	52	94	27	15

Type of Abuse Experienced
(not mutually exclusive categories)

	Physical Abuse	Sexual Abuse	Neglect	Emotional Abuse "only"	At-Risk
#	90	33	163	9	26

Similarly, it might have been expected that a majority of the referrals would come under the "neglect" category. The proportion of sexual abuse cases, however, was not accurately anticipated. In preparation for this project, statistics were reviewed indicating that probably 6 to 7 percent of the referrals would be of this category. As the project proceeded, a larger proportion was apparent with the current 13.2 percent nearly doubling expectations.

The number of at-risk diagnoses was likewise impressive. Clearly there are some preventative considerations here in that at-risk status demands precautionary interventions. This may be explained in part by the referral situation where care and protection agencies were confronted by a combination of problems. They needed more comprehensive professional team review and additional consultation in order to correct troubling situations which might easily intensify.

The foremost observation derived from review of this activity was that a

majority of the children referred were actually not retarded. Since there were often complicated and multiply interacting problems, these have to be reflected upon from several perspectives. Taking a very strict criteria of Child IQ 69 and below, only 26% of the referrals would meet the criteria of being retarded. However, the at-risk nature of many of the other children, some of whom were very young, must be considered. Also some were extremely anxious or only shortly removed from overtly upsetting environmental circumstances. However, looking at Table 2, it is clear that even with these allowances a majority of the children referred actually had average ability or better.

Table 2

DEVELOPMENTAL DISABILITIES AND CHILD ABUSE PROJECT

First 250 Children Evaluated

Primary Diagnosis of Children Evaluated

Impression	Number of Children
No Current Problems/At-Risk	19
General Developmental Delays	34
Borderline Intelligence	22
Mild Mental Retardation	35
Moderate Mental Retardation	11
Severe/Profound Retardation	7
Unspecified Mental Retardation	1
Pervasive Developmental Disorder	11
Language/Learning Disability*	37
Non-verbal Learning Disability*	2
Emotional/Behavioral Problem*	68
Thalassemia (Blood Disorder)	1
Deferred Diagnosis	2
TOTAL =	250

*(clearly of average IQ)

A related and serious concern that became apparent in this project was that of "limited parents." These were parents with borderline or below IQ scores, having sometimes effectively learned to "pass" very well with effective routines or the help of benefactors, but dismally failing to grasp parenting demands.

Not all had limitations which were cognitive in nature. Some parents were very emotionably unstable individuals; others blatantly psychotic or habitual substance abusers. However, the concern was similar to involvement with other social problems: that these "limited parents" were incapable of carrying out child-rearing responsibilities without imposing some harm on their offspring.

The limited parent problem area was found to be a major one confronting many of the agencies with which contact was established. As a result, some open discussions on this topic were sponsored and representatives of both private and state agencies were invited to attend and contribute suggestions for confronting the problem. Eventually, three annual regional conferences were conducted and the topic was the subject of the regularly scheduled meetings of a broadly supported state interagency task force to address some of these issues.

Implications for Title V and UAFs

In regard to this project we found there were four areas about which some conclusions might be drawn:

1) In consideration of child and family health issues and in relation to many Title V concerns, it is self-evident that the complex relationship of child abuse with developmental disabilities centers around at-risk situations. The complexity of these situations demands the breadth and planning capacity of skilled interdisciplinary teams. The preventative aspects are derived through the corrective planning efforts and the individualized service direction involved in such comprehensive review. The model team for this project was designed mainly for working with, and complementing, care and protection efforts. In the physical abuse areas more medical involvement, particularly to treat injury or traumatic emergencies, is essential. However, the team cannot

proceed on too narrow a biological model. It must be open to consider all aspects of emotional adjustment and life management.

2) Similarly the team must be open to interaction with all aspects of the social spectrum. This is the arena in which current public health efforts take place. Several states have assigned their early intervention programs to public health departments, linking them with allied Maternal and Child Health programs. The Children's Bureau of the first half of this century made its historic contributions by confronting many seemingly insurmountable public health problems which had been considered inseparable from social issues. Today's challenges lie in the arena of broader social involvement. Child abuse, accident prevention, and family support all have closely allied programs in public health. The comprehensive progress of the interdisciplinary team was designed to produce resolution and remediation when focused on issues which have previously defied interventive efforts. The interdisciplinary team, for the sake of its own self-motivation, reward, and evolution, needs to be out where the action is.

3) In regard to the mental retardation field, the teams must recognize that the majority of the MR population remain classified under the "unknown cause" category. This reflects the complex interaction of cognitive limitations combined with many physical, social, and emotional problems. However, this challenge of an unclassifiable majority also should be faced by interdisciplinary team investigation through research means. The issues are two-fold. Perhaps, to a degree, the unknown percentage should be reduced by intensified and more refined diagnostic approaches. But even after these efforts produce their desired results, probably most cases will remain "of unknown origin." Rather than ignoring the significance of this majority because it is not neatly scientifically labeled, perhaps what interdisciplinary teams need to do is promote order among the chaotic elements by facing specific

issues, such as: Are there more definitive approaches or considerations that can be derived for this diagnostic group? Are there particular assurances that families need when first encountering such an admission from respected professionals from whom they are expecting more precise answers? Are there commonalities that can be found which will promote living with a problem of unknown origin and which will reduce the stress of worry which this admission inflicts upon parents?

4) Lastly, is the acknowledgement which diagnostic teams must give to the interaction between dependent child and the variables which influence the intensity and forms of human nurturance. The interdisciplinary team has the comprehensive capacity to plan effective change in life management on a very broad scale. It should be self-evident that this will be achieved more effectively and more often be successful when the team proceeds with a very important recognition: that the human organism is a social creature whose functional capacity is immersed in, and shaped by, an environment which in today's world is controlled, and to a degree determined, by very powerful social forces.

Author's Note: Appreciation is expressed to all co-workers of the child abuse Developmental Support Team: Jane Snyder Ph.D. (Team Coordinator); Ann Murphy M.S.W; Ludwik Szymanski M.D.; Bruce Eissner M.D.; Marie Cullinane R.N., M.S.; Anthony Bashir Ph.D.; and Jean M. Zadig Ph.D. Of course all benefited from the prevailing encouragement and moral support of our UAF Director Allen C. Crocker, M.D.

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II.
A CONSIDERATION OF LINKAGES

A COMMUNITY COLLABORATION APPROACH FOR DEVELOPING EARLY INTERVENTION SERVICES IN OKLAHOMA

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Purpose

This three-year SPRANS project is a collaborative effort between the University Affiliated Center in Dallas and the Oklahoma State Department of Health, the lead agency in Oklahoma.

The purpose of the project is to improve early intervention services in Oklahoma through:

- facilitation of a grass-roots approach to service delivery and
- simultaneous promotion of interagency planning and coordination at the state program level.

Audience

The products of the project and experience to be shared through those products are intended for (a) professionals and administrators of federal, state, and local programs with responsibilities for children with developmental disabilities and chronic illnesses and their families; (b) professionals in UAFs; (c) parents of children with developmental disabilities and chronic illnesses; and (d) others who are interested in intervening on behalf of children with special needs.

Procedures

The project staff consists of the project administrator with the University Affiliated Center and the project coordinator with the Oklahoma State Department of Health. They are serving as catalysts or external facilitators for

organizing local community teams; they are also providing resources and ongoing technical assistance for the local teams. In a parallel effort, the project staff is working with state program administrators and others in establishing coordinated planning and program development at the state level.

In developing the local community teams, emphasis is given to developing a local sense of responsibility for problems and ownership of solutions; involvement of parents, volunteers, and community leaders; and involvement of the private sector as well as the public agencies which serve developmentally disabled and chronically ill children. Through a "networking" approach, local leadership is identified and their involvement in further networking of the community solicited. The facilitators participate in the initial organizing meetings and the early meetings of the task forces defined by each community team. They are available as consultants to each of the teams, participate in meetings as requested by the local team members, provide resources, and act as brokers and facilitators to the teams.

Results to Date

Six community teams have been established and organization within an additional community was begun in the Fall of 1986. Among the communities, there is a balance of large urban, non-metropolitan, and rural classifications. Special attention is being focused now on the service delivery problems and solutions for families living in rural Oklahoma.

There are strong components of volunteerism and parent participation on each of the local councils. Two of the teams have a parent and a physician as co-directors. Although there is neither a state mandate nor funding for their efforts, each of the community teams is highly active in seeking improvements in services to special needs children. One council has raised about $8,000 from private donations to help fund a statewide information and referral system for

services to handicapped children. In another community, two of the public agencies have collaborated to increase the number of day care resources for children with special needs. Three committees or subcouncils have been formed to identify and address the special needs of families of minority cultures. Although the local teams have been functioning for a relatively short time, there is some evidence of increased awareness of resources in the community, changes in the referral patterns, and, in the case of the earliest of the community teams, the beginnings of a case management approach.

The project has performed a significant role in the development of increased interagency coordination among state programs. This is exemplified by the completion of a statewide needs assessment as an interagency endeavor. It is also reflected in the planning and initiation of the statewide information and referral (I&R) system. The I&R system is being funded through public and private contributions, involving state and local resources.

A state advisory council with representation of parents, local communities, and the state agencies has been formed. The advisory council is actively planning the longer-range development and implementation of early intervention services across the state. The Oklahoma Commission for Children and Youth has become the focus for planning and coordination of early intervention services in Oklahoma. The Commission is an interagency body with representation of health, human services, education, mental health and other state agencies.

As the process of developing local community teams has progressed, the learning experience have been used to streamline the process. As a result, the time required to organize a local community team has been significantly reduced. The process has been incorporated into the state plan for developing regional and local community teams throughout the state during the next five years. A plan has also been developed and measures selected to assess the impact of the

approach on outcome variables over the five-year period.

Products

A "procedural guide" will be completed and disseminated by June 1987. The content will focus on specific tasks that the local community team must typically accomplish. These include involving parents, developing funding strategies for the operation of the team, and implementing a public awareness campaign. The guides are being designed as additions to the existing resource materials. Copies of the guide will be disseminated to UAFs, advocacy groups, state MCH and CC programs, and to other state and federal programs concerned with early intervention services. Information on obtaining additional copies of the guide will be provided with a complimentary copy.

TOWARD STRENGTHENING NUTRITION SERVICES IN REGION IX FOR CHILDREN WITH CHRONIC ILLNESS AND HANDICAPPING CONDITIONS

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Purpose

The purpose of this continuing education project is to use the format described in Nutrition Services for Children with Handicaps: A Manual for Title V Programs to assist the states within DHHS Region IX (Arizona, California, Hawaii, and Nevada) strengthen the delivery of nutrition services to children with chronic illness/handicapping conditions. In California, the project will focus on Los Angeles and Imperial Counties only.

The project has been conceived as a two-year sequential plan, beginning with a regional needs assessment which will provide a Regional Advisory/Planning Committee, consisting of key persons from each state/county, with information necessary to design a regional conference. The conferences will have two major goals:

1) to provide technical information on topics of relevance, in response to identified regional training needs.
2) to provide a forum, and the necessary resources, for participants from each state/county to develop a five-year plan for strengthening nutrition service delivery to children with handicaps. In addition, the plan for the first year will contain specific, time-framed activities leading to well-defined objectives, however preliminary these may be.

As a result of the needs assessment, the planning process, and the first stages of implementation, state/county-specific training and/or technical assistance needs were identified. To respond to these, separate workshops were

planned and held by state/county working groups established at the regional conference. They were designed to provide guidance, improve skills, facilitate utilization of local resources, or to develop interdisciplinary team function. At their second meeting, held toward the middle of the second year, the Advisory/Planning Committee discussed progress with the state/county implementation plans, and designed the follow-up regional conference which will focus on evaluation, data management, and monitoring. The design was also based on consideration of feedback from the first conference and the state/county workshops.

Accomplishments

Regional needs assessments were conducted in all states and counties in which the project is operated. Based on the needs assessments, workshops on planning for improving nutrition services were planned and held. At the workshops, participants developed 5-year plans for services with specific objectives and activities for the first year. In the second year, implementation plans were developed and workshops held in each state or county to respond to training needs necessary for implementing the plans.

Services have been improved in a number of ways, ranging from hiring additional personnel at the state level to training local staff (non-nutritionists) to do nutrition screening. Interdisciplinary, interagency pilot projects have been implemented in Los Angeles County and Nevada to carry out screening and referral for intervention. In a number of places, the project has facilitated the establishment of active interagency networks.

Products

At completion, there will be several products for dissemination.

1) Plans for strengthening nutrition services for children in

the Region IX CCS programs, including profiles of nutritional needs, services and resources, and a five-year implementation plan;

2) Reports from each state/county on

   a) First year implementation plans; and

   b) identified future training needs;

3) Proceedings of the Regional Conferences and the State/County Training Workshops; and

4) Video-tapes of selected presentations/group sessions from the Regional Conferences.

YOUTH IN TRANSITION PROJECT

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Overview

Adolescents who have chronic or lifetime disabilities are at risk for poor adjustment in their transition to maturity because of lack of attention to health and family concerns. Difficulties resulting from inappropriate sexual behavior, poor hygiene and grooming, unattended health problems, obesity, conflicts in family relationships, and lack of understanding and acceptance of disabilities by the youth and their families frequently cause and/or contribute to failure of vocational and independent living plans.

All too often adolescents with lifetime disabilities receive only those health services which focus on their specific disability. Specialists who provide care for disabilities like these are often not skilled or even interested in normal adolescent health issues, while the general providers of adolescent health care may not be comfortable in dealing with the problems associated with lifetime disabilities. In addition, programs that do provide comprehensive services, including focus on health and family issues for persons who may have chronic disabilities are generally available only for young children with a primary emphasis on the preschool years.

Procedures

The Youth in Transition Project (YTP), a three-year SPRANS project, is designing and implementing a program to bring about greater integration between health care, education, and vocational specialists. Using the facilities of the Adolescent Medicine Clinic at the University of Washington Child Development and

Mental Retardation Center, the project will complete health and psychosocial evaluations for 40 young adults, ages 17-21, who have chronic or lifetime disabilities. During the first year of the project the interdisciplinary team, consisting of a nurse, nutritionist, physician, psychologist, and social worker, developed data collection instruments and assessment protocols to be used in the evaluations. Protocols were also established for patient recruitment and for the Puget Sound Community (representing education, vocational, health care, and residential facilities) to enlist their assistance in referring patients to the project. Information was also gathered on resources in the community that would meet the multiple health and psychosocial needs of the population of young adults in transition.

During Year II, the YTP has accepted 37 youth for assessment and has completed evaluations on 26 youth and their families. Primary sources for these referrals have been schools and the Division of Vocational Rehabilitation. Barriers in recruiting youth with health impairments have been encountered. The lack of a tracking system for clients of the State and County Health Departments has precluded identification of youth with chronic health problems who had received services in the past. An additional barrier in reaching these youth was the perception, of several of the specialty clinics at Children's Hospital serving youth with health impairments, that the services in this project were either overlapping or competitive with what they provide. This led to a reluctance in some cases to refer patients to the project.

These barriers were overcome by working closely with school, vocational rehabilitation personnel, and general health providers who could identify youth with chronic health impairments. In addition, collaboration was established with the Pediatric Pulmonary Center at Children's Hospital to assist in identifying potential project participants.

The project has had requests to provide services for youth with chronic

emotional problems which could not be addressed due to lack of adequate support and ongoing counseling and psychiatric services. However, several young people with serious mental health problems who had ongoing support services have been included in the project.

When a prospective patient's advocate contacts the clinic, an intake interview is conducted on the phone, and this information is discussed at the weekly YTP Team Meeting. Once a patient has been selected for the project, he/she and his/her family are seen by each member of the interdisciplinary team. The young adult is given a complete physical examination and nutritional assessment, and is interviewed by the psychologist and social worker. Psychological testing is administered if necessary, as are consultations from psychiatry, neurology, and dentistry. Parents and other care givers are also interviewed with special emphasis on their perception of issues around the transition from adolescence to adult status: completion of school, employment, independent living. After the 1- to 2-day evaluation, project staff pull together assessment information and identify specific health and psychosocial issues that have direct bearing on transition. During a conference these issues are discussed with the patient and family and recommendations for a transition plan are made with specific attention given to immediate service needs that will enable an easier transition.

Outcome

A wide range of previously unidentified and/or untreated health and family issues have been identified as a result of the evaluations of youth in this project. These have included inadequate nutritional status, obesity, lack of birth control, poor hygiene and grooming, excessive dependency in adaptive living abilities, question of early Alzheimer's disease, chronic back pain,

enuresis, and problems in separation from family enmeshment. Each of these areas, if left unattended, would present increased risk for lack of sucess for vocational and independent living plans. In addition, project activities, protocols and experiences have been shared at local, regional, and national meetings with a wide range of professionals. This has included presentations and meetings to increase the understanding and skills of professionals to attend to health and family concerns of youth in transition, thus improving the health and quality of life for the target population.

Future Plans

Data gathered from the assessments will be used to develop a model protocol for use by health and social service providers. Included will be information for use by educational and vocational specialists regarding referral for health and social services and how best to work with other providers to serve adolescents in transition and to assist them in assuming functional adult roles.

The third and final project year will focus on the dissemination of a manual, developed as a part of the project, for health care, social service, educational, and vocational specialists serving adolescents in Washington State and other states in Region X. The manual will be developed by aggregating the data from the patients seen by the project to inform care givers of the kinds of problems transitional youth in this population present. Care plans, assessment tools, and a bibliography will also be part of the manual. Four workshops will also be held in Region X for providers from each of the service areas.

An Advisory Board with participants from Maternal and Child Health, Crippled Children's Services, Vocational Rehabilitation, the Office of Public Instruction, and the Developmental Disabilities Planning Council has been meeting regularly and monitoring the relevance of project activities. When the time comes for distribution of project products, agency members of the Advisory

Board will contact their counterparts in other states within Region X.

The health status of adolescents in Region X will be improved as a result of this project. Increased awareness, understanding, and attention to the health and family issues of chronically disabled youth by health care providers and increased collaboration between health care providers and education and vocational professionals will insure that more and better services become available. These changes will lead to greater early identification and treatment of "normal" health problems among chronically disabled youth which will improve their health status overall and increase their potential for successfully achieving their maximum potential as adults.

CONTINUING EDUCATION FOR OCCUPATIONAL THERAPISTS WORKING WITH CHILDREN AND THEIR FAMILIES

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Purpose and Audience

The purpose of the project was to provide a short-term collaborative and multifaceted continuing education program for occupational therapists (OTs) working in Maternal and Child Health programs across the nation. The education experience was designed to provide needed resources and skills. These will enable participating OT's to take leadership roles in organizing and testing for effectiveness and developing innovative occupational therapy programming responsive to the health care needs of mother and children. The project represented a collaborative effort among University Affiliated Programs (UAPs) nationwide, Children's Hospital of Los Angeles, California Children's Services, and the University of Southern California. The program format was two annual conferences, January 1986 and 1987, with related pre- and post-conference activities.

The focus of each year's conference was on participation, networking, research, and leadership development. The conferences were planned to provide appropriate learning experiences for occupational therapists at various points in the practice of their profession from student to leader.

Procedures

The first conference focused on development of clinical research skills, leadership and networking. Sixty-six presentations were made by 100 persons representing national and local leaders in occupational therapy, school

administration, physicians and administrators of Maternal and Child Health (MCH) programs, the American Occupational Therapy Association (AOTA), OTAC, regional centers, school systems, an insurance company, universities, the UAP, CCS and community occupational therapists. Thirty-five national and local leaders in occupational therapy gathered to discuss current issues related to occupational therapy and MCH. Thirty-four poster presentations were made on clinical applications of occupational therapy and clinical education.

One of the foci of this project was to facilitate research between directors of occupational therapy at UAFs. The research emphasis was on clinically based studies to document the efficacy of occupational therapy in maternal and child health and developmental disabilities. Single subject research design was chosen as the most appropriate research methodology for this purpose. This is a systematic way of analyzing, measuring and evaluating practice. It offers opportunity to occupational therapists at the UAPs across the country to demonstrate their accountability and the validity of the intervention procedures utilized in individual and small group practice. This method is also "do-able" by therapists with heavy patient loads.

The grant provided the opportunity for the researchers to: 1) be trained in single subject research; 2) be mentored as they implement their search; 3) report and publish their research; and 4) to evaluate the utility of this research methodology in a clinical setting. As a result of the conference, thirty-four persons made the commitment to carry out single subject research during the year of January 1986 to January 1987. Twenty-four of these were occupational therapists from UAPs across the nation. The training included: 1) pre-conference activities - picking a research topic and reviewing the literature; 2) participation in a national conference with other researchers for training and protocol design; 3) research implementation; 4) participation in a second national conference to report research and evaluate the process; and 5)

publication of research results in conference monographs.

The second conference focused on presentation of research results, leadership development, and networking. In addition, presentations on animal research relating to occupational therapy and MCH problems offered a stimulus to the experienced researcher attending as a leader and as inspiration to the beginning researchers representing the extent to which occupational therapy research can go. Sixteen research projects were presented by twenty occupational therapists who had participated in the first year's conference. Leaders and mentors discussed each project offering guidance in the research process. Ten poster presentations of clinical settings were displayed. Networking and leadership development were also provided through informal and individual roundtable discussions with the forty-eight leaders from across the nation who attended.

Results to Date

Both conferences have been held resulting in new networking nationwide of leaders, researchers, clinicians and students in UAPs, and pediatric occupational therapists. Twenty researchers generated seventeen research projects using single subject design. A computerized data base on efficacy studies in occupational therapy, on pediatric occupational therapy clinical programming, and interdisciplinary training procedures has been initiated. Videotapes on the training conference have been produced.

Products

Proceedings for both conferences will be available through the American Occupational Therapy Association: 1383 Piccard Drive, P.O. Box 1725, Rockville, MD 20850.

NEW DIRECTIONS: SERVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN MASSACHUSETTS

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Introduction

Funded by the Division of Maternal and Child Health, Project SERVE has worked for three years to review the public mandate for services to children with chronic illness and disabilities. The program was conducted jointly by the Developmental Evaluation Clinic (UAF) at the Children's Hospital, the Department of Maternal and Child Health at the Harvard School of Public Health, and the Division of Family Health Services of the Massachusetts Department of Public Health. Extensive recommendations were made for an improved system of family and child support, including a larger population of children than has been usual for Title V activities.

As part of the final project, a public hearing was conducted at the State House in Boston on December 12, 1986, in which families, providers, and agency workers were invited to express their convictions regarding the special circumstances of chronic illness in childhood. The following platform was used as a basis for discussion. It is the anticipation of Project SERVE that Massachusetts will take a leadership role in more effective family support and fiscal advocacy in this area.

Unlocking Resources for Children with Special Health Care Needs: A Platform for Reform in Massachusetts

All children deserve the right to grow in an environment that encourages their optimal growth and development. This statement applies to healthy and able-

bodied children as well as children who have significant long-term illnesses and chronic disabling conditions. However, access to appropriate health care is not yet a guaranteed right for children in our nation. There are thousands of children in the Commonwealth with a chronic illness or disability who are completely uninsured or who have inadequate benefits to cover their extensive service and treatment needs.(1)

Who Are The Children?

These are children with a chronic illness - cystic fibrosis, hemophilia, diabetes, and leukemia, or a disability such as cerebral palsy, spina bifida, or cleft palate. Health care is expensive for everyone, but for a family with a chronically ill or disabled child, the costs may be overwhelming.

Though approximately 10-15% of Massachusetts children have some form of chronic health condition, most of these are mild and interfere only to a small degree with the child's usual daily activities. However, 5% of Massachusetts children (100,000 children) are estimated to have a condition which will require specialized health and related services. Of these, 2% of Massachusetts children (40,000) are estimated to have severe chronic health conditions which can be expected to create special burdens for the child and family.(2)

There are more than 600,000 uninsured persons in Massachusetts and one third of these are children. As many as 10,000 of these uninsured children have a chronic illness or disabling condition which makes access to health care even more critical.

What Are The Needs?

Recent studies in Massachusetts and other locations indicate that this group of children needs a comprehensive set of family and community oriented services.

Even when insured, many families face high out-of-pocket expenses for services such as medications, adaptive equipment, home health care, and long-term occupational therapy, physical therapy, and speech therapy which are not covered by their benefit packages.(3) Case management and service coordination are critical components of quality care for children who are served by multiple agencies and providers. Respite care, financial counseling, and a wide range of family support services are required to support the role of parents as care-giver and partner in the delivery of health care.

Limitations on benefits such as lifetime ceilings, co-payments, and annual benefit caps pose significant hardships to families caring for a child with a long-term illness. Such barriers to adequate health care must be removed.

Chronic illness creates special jeopardy for poor children, doubling the likelihood that the child living below the poverty line will lack access for any form of health insurance.

What Can The Commonwealth Do?

In order to protect these children and their families there must be expanded public funding to increase access to adequate and affordable health insurance. In addition, there must be a system which establishes standards and monitors the quality of specialty care. Finally, the Commonwealth must provide a broadened range of services and guarantee system which respects the rights of children with special health care needs and their families.

In order to reform the health care financing system and to expand the role of the Commonwealth in providing services, the following platform is proposed.

1. Health Insurance for All

The Commonwealth must guarantee access to comprehensive, affordable coverage for all children with special health needs, regardless of pre-existing medical conditions, age, likelihood of need for medical services, family structure, or

conditions, age, likelihood of need for medical services, family structure, or employment status. An improved system for health care financing must meet the following criteria:

- o Integrated Planning: Solutions designed for this specialized population must be created in conjunction with solutions for the general population of the uninsured.

- o Multiple Funding: Funding for this sytem must come from multiple sources including private insurers, Medicaid, hospitals, employers, and state and federal agencies.

- o Supplementary Benefit Package: Access to comprehensive benefits should be delivered through a supplementary wrap-around package designed to meet the needs of this population. An extended benefits package must include services such as home health care; adaptive equipment; medications; specialized orthodontia; hospice care; long-term occupational therapy, physical therapy, speech, language and hearing services; and preventive mental health services.

- o Affordable Premiums: Cost of premiums should be based on income, and not on individual health risk factors.

- o Prohibit Discrimination: Private insurers must not be allowed to discriminate against individuals based on disabilities not associated with medical risk.

- o Continuity of Benefits: Movement in and out of employment or changes in income status must not jeopardize continuity of health insurance benefits.

- o Consumer Participation: Mechanisms should be established which ensure consumer participation in governance and access for complaints and redress of grievances.

- o Consumer Choice: Individual selection of health care providers and access to appropriate specialty care must be protected while perserving the goal of coordinated health care.

- o Cost Containment: The health care financing sytem should encourage delivery of services in the setting that provides quality care at the lowest cost.

2. Expanded Public Service System

Expanded public programs for children with special health care needs must include: quality assurance for specialty health care, interagency coordination and individual service planning, and provision of needed support services not covered by health insurance. Enhanced public service programs must include the

following components:

- Public Advocacy: Advocacy for children with special health care needs must be provided by the Executive Office of Human Services through its operative agencies, with leadership from the Massachusetts Department of Public Health's Division of Family Health Services.

- Standard Setting and Program Certification: Standards which define quality specialty health care for children must be adopted by all payors (both public and private). The standards must guarantee a strong consumer role in both the design and delivery of these services. Specialty services for children within managed care systems as well as fee-for-service systems must be certified.

- Support Services: An expanded array of support services required by children with special health care needs and their families must be provided. These services should include: case management, information and referral, early identification and screening, early intervention, family support, nutritional counseling, respite care, housing adaptation, individual service planning, parent-to-parent support, prevention, and parent training and education.

- Information and Health Education: Public agencies must inform consumers and providers regarding individual rights and entitlements and standards which define quality health care.

- Interagency Service Coordination: Public programs must ensure the coordination of health, education, and social services necessary to maximize the effectiveness of those services and through the development of individual service plans, involve all participating agencies while acknowledging the central role played by the family. These plans should be provided for children receiving service from two or more agencies.

- School-Based Health Services: Cooperative agreements must be established between the Department of Public Health and the Department of Education which ensure access to school-based health services for children with special care needs.

3. Consumer Roles, Rights, And Responsibilities

Consumer organizations outside the public system should be involved in assisting families with information and support. Families and such voluntary organizations should participate in a partnership with public agencies so that facts and up-to-date needs can inform the designer of services and policies. Families of children with special health care needs must also be guaranteed certain rights with regard to their child's health care. These include:

- The right to be treated with respect and dignity in obtaining health care for their child.

- The right to be a full partner in the design and delivery of health care for their child.

- The right to receive clearly written and understandable insurance policies which fully define benefits.

- The right to the delivery of health care services in a manner which supports the integrity of the family. This includes the right to coordinated community-based services and support services and the right to protect the fiscal integrity of the family unit.

The views expressed in this platform are solely those of Project SERVE, Massachusetts Health Research Institute, Inc., and should not be construed as necessarily representing the opinions or policies of any other agencies or advocacy groups in Massachusetts.

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